DISRUPTIVE BREAST CANCER NARRATIVES: SHAPING CULTURAL POLITICS, INFORMING FEMINIST BIOETHICS AND PERFORMING REPAIR

by

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Abstract

This project explores the narration of experiential knowledge about breast cancer arguing that personal narratives, in the form of “disruptive breast cancer narratives,” have the potential to shift public perceptions, breast cancer culture and biomedical understandings of the disease. In Chapter 2, I explore the potential of narrative enquiry in qualitative health research and establish my interdisciplinary framework which turns to patient-centred knowledge creation, affective illness histories and archiving feelings as well as cultural studies of the body, critical gender and sexuality studies. Chapter 3 outlines my theoretical approach to disruptive breast cancer narratives and involves an exploration of the scholarly potential and limitations of illness narrative study and turns to narrative approaches to feminist bioethics. Chapters 4, 5, and 6 explore disruptive breast cancer narratives through close readings of narrative texts. In Chapter 4, I examine feminist anger through Barbara Ehrenreich’s (2001) “Welcome to Cancerland,” Audre Lorde’s (1981) The Cancer Journals and Kathlyn Conway’s (1997) Ordinary Life. In Chapter 5, I read Wendy Mesley’s (2006) Chasing the Cancer Answer and Kris Karr’s (2007) Crazy Sexy Cancer as documentary films that purport to disrupt the dominant discourses of breast cancer by exploring them in relation to discourses of personal responsibility and a figure I call the “cancer killjoy.” In Chapter 6, I begin with an examination of Eve Sedgwick’s (1993) “White Glasses” which provides a powerful critique of how gender and sexuality are constituted through a breast cancer diagnosis and treatments and advance this critique through readings of Catherine Lord’s (2004) The Summer of Her Baldness and the television drama The L Word (2006); this chapter is guided by S. Lochlann Jain’s (2007a, 2007b) conception of “elegiac politics.” My project concludes in Chapter 7, by exploring the potential of counternarratives of illness and of performing resistance, patienthood and narrative repair; here, I necessarily reflect on my own experience of chronic illness.
Preface


This publication was then selected for reprint, edited for clarity, and now is a forthcoming publication in a women’s and gender studies textbook. Nielsen, E. (2013). Feeling angry: Disruptive breast cancer narratives, cancer prevention discourse and public affects. In B. Cranney and S. Molloy (Eds.), *Canadian woman studies: An introductory reader (3rd edition)*. Toronto, ON: Innana Publications.
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1 Disruptive Breast Cancer Narratives: Shifting Public Perceptions, Discourses and Cultures of Disease

1.1 The Public Narration of Disruptive Breast Cancer Narratives

This project is about subjectivities, illness narratives, and emotions and how these otherwise discrete entities coalesce in the public stories about cancer I term “disruptive breast cancer narratives.” It is a project about breast cancer culture, injured bodies, angry performances contained within personal narratives, and the potential of performativity to illuminate the sociocultural, textual, and subjective aspects of autobiographical stories. This project theoretically engages with narrative approaches to feminist bioethics (Nelson, 1997), the cultural politics of emotion (Cvetkovich, 2007; Ahmed, 2004) and especially feminist anger (Ahmed, 2010; Woodward, 2009; Boler 1999; Lorde, 1980), and the potential personal narratives have in repairing subjectivities injured by the master narratives told of illness (Nelson, 2001) and, specifically, breast cancer diagnosis and treatment (Bryson, 2009). In this project, I will explore how these publicly disseminated counternarratives of breast cancer can be read to contribute to patient-centred cancer knowledge creation and how recent knowledge is explicitly about the body and articulated from feminist and queer subjectivities, perspectives and experiences (Bryson & Stacey, 2013; Jain 2007a, 2007b; Sedgwick 1993). In fact, such disruptive breast cancer narratives can also be understood to individually and collectively form “an archive of feelings” (Cvetkovich, 2003). In such an archive, personal narrative, experiential knowledge, and emotion meet and have the potential to shift dominant perceptions, discourses, and cultures of breast cancer.

Certainly, narratives of breast cancer have become increasingly common in a historical moment that explicitly encourages the telling and dissemination of emotionally
charged autobiographical stories (Segal, 2007a; Herndl, 2006; Ehrenreich, 2001). The American Cancer Society’s (2012) “Tell Your Story” campaign solicits a particular type of cancer narrative when asking for “inspirational stories” to provide “hope,” “comfort and courage” for the many lives “touched” by cancer. Here, the ACS asks for iterations of “the standard story of breast cancer,” a narrative type that dominates public discourse of the disease (Segal, 2007a, p. 4). There are reasons to resist standardized cancer stories of hope and courage if only because for many a breast cancer diagnosis is fraught with the conflicting emotions of anxiety, anger and sadness. Notably, social critic Barbara Ehrenreich (2001) first publicly resisted the standard story of breast cancer when she wrote “Welcome to Cancerland,” a personal account of the disease published in *Harper’s Magazine*. Here, she questions the publicly acceptable feelings a cancer patient can express, observing that “so pervasive is the perkiness of the breast-cancer world that unhappiness requires a kind of apology” (p. 48). 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” (p. 53).

When the ACS asks on its website for “inspirational” cancer stories, what can be inferred is that uplifting narratives with a happy ending are very welcome. Yet in only making space for the sharing of cancer stories with positive outcomes, other types of cancer narratives are effectively silenced. Unfortunately, not every person who receives a breast cancer diagnosis will also experience successful treatment and recovery from the disease. *Canadian Cancer Statistics 2011* reports that 1 in 9 Canadian women is expected to develop breast cancer within her lifetime, and 1 in 29 is expected to die from the disease (p. 59). In 2011 alone, 23600 new cases of breast cancer were diagnosed, and 5100 deaths were reported
In the documentary film, *Chasing the Cancer Answer* (2006), journalist Wendy Mesley resists normalizing current cancer statistics when she asks why more is not done to prevent cancer in the first place. With almost 1 in 2 Canadians diagnosed with cancer within their lifetimes, Mesley refuses to accept that current national cancer prevention strategies are truly effective. In reporting on her own experience with breast cancer, Mesley chooses not to tell an inspirational story because she is troubled by inaction where collective cancer prevention is concerned. While *Chasing the Cancer Answer* does not singularly focus on Mesley’s diagnosis and treatment, elements of her personal story are revealed, as are factors that may have potentially increased her cancer risk despite living a Canadian Cancer Society (2012) approved “healthy lifestyle.” Moreover, both Ehrenreich and Mesley disrupt the standard story of breast cancer in publicly presenting narratives of experiential knowledge punctuated by performances of negative affects; in this way, they defy the “tyranny of cheerfulness” in breast cancer culture (King, 2006, p. 101).

To this end, this study of disruptive breast cancer narratives will illustrate how experiential stories of breast cancer can function in opposition to “agnotology” or “the cultural production of ignorance” as has been previously argued of breast cancer narratives (Segal, 2007a). It remains important to theorize what we conceptualize as “experience,” especially because it is the writer’s experience of illness that is put forth as the primary kind of evidence readers are asked to accept as uniquely qualified information (Smith & Watson, 1998, p. 27). This project will undertake to explore the complexity and problematics of claiming personal experience, subject formation, and identity in relation to breast cancer, and will read breast cancer narratives via a theoretical framework that incorporates narrative approaches to feminist bioethics, and theories of performance and performativity, as well as
critical gender and sexuality studies. In so doing, this project explores breast cancer narratives through interdisciplinary study and seeks to contribute to the scholarly terrain of qualitative health studies. As such, this project queries how disruptive breast cancer narratives are currently informing and changing public perceptions of the disease as well as a breast cancer culture formed in relation to dominant discourses such as biomedicine. In seeking to highlight the narrative repair breast cancer narratives can do, it quickly becomes clear that the personal aspects of breast cancer narratives need not necessarily produce or reproduce ignorance about the disease.

Breast cancer narratives can offer differing experiences and perspectives on breast cancer as a disease and a culture; importantly, from patients who are affected by, but aslant to, biomedical knowledge. Yet the “disruptive” aspects of these stories can only surface and form disruptive narratives if multiple ways of telling a breast cancer narrative are encouraged in public discourse rather than shut down simply because these narratives are inextricably connected to personal experience. Disruptive breast cancer narratives are formed in relation with and in response to standardized storytelling about cancer; I will illustrate throughout this project that disruptive breast cancer narratives are heterogeneous in perspective, theme, and tone. Contained within disruptive breast cancer narratives, are questions of how to perform patienthood and survivorship in the public sphere, as well as the ways emotion, gender, and sexuality in relation to breast cancer diagnosis and treatment all become necessarily complicated, relational, and questioning (Bryson & Stacey, 2013; Jain 2007a, 2007b). Indeed, emotion, gender, and sexuality are all intimately intertwined in these narratives as the autobiographical self both performs and is performative in “acting out” and “talking back” to normative constraints found in the mainstream of breast cancer culture.
Langellier (1999) suggests applying the insights of performance studies in autobiography and life writing, as a way through an oppositional terrain that either celebrates personal narratives or continues to read them with suspicion (p. 130). Langellier argues that both “performance and performativity open a pathway through the celebratory and suspicious terrain of personal narrative” (p. 130). This perspective is manifested in feminist and queer theories, critical studies in autobiography and life writing, and by writers, filmmakers, and performance artists where personal narrative is deployed as embodied and material, situated and self-reflexive, critical and complex. At best, these efforts “do not underestimate the transformative power of personal narratives but neither do they romanticize its claims to resistance” (Langellier, p. 130). Approaching personal narratives as instances of textual and cultural performance requires a theoretical frame which takes “context as seriously as it does text, which takes the social relations of power as seriously as it does individual reflexivity, and which therefore examines the cultural production and reproduction of identities and experience” (Langellier, p. 128).

In seeking to contextualise the power of personal performances contained within autobiographical texts, it is very important to examine how performativity can function within these personal narratives. “As soon as performativity comes to rest on a performance,” Elin Diamond (1996) stresses, “questions of embodiment, of social relations, or ideological interpellations, of emotional and political affects, all become discussable” (p. 5). These issues become discussable, in part, through being detached from reductive conceptions of how “the personal” functions within personal narratives. For “the personal in personal narrative implies a performative struggle for agency rather than the expressive act of a pre-existing, autonomous, fixed, unified, or stable self which serves as the origin or accomplishment of
experience” (Langellier, 1999, p. 129). Performativity, as a theoretical concept, has the potential to explicate and situate personal narratives within powerful discourses that function to shape subjectivities, while performance, carried out in everyday acts, calls on a “transgressive desire” for both agency and action (Langellier, p. 129).

The public conversation on breast cancer continues to demand revitalization and proliferation. At the same time, this discourse is being positively changed and shaped by public breast cancer narratives (Knopf-Newman, 2004). The time may well have passed for the simple rehearsal of breast cancer’s standard storyline. Still, those who write an experiential narrative of breast cancer—another version of the standard story or a more disruptive one—are, because of a diagnosis and treatments endured as patients, outside of traditional centres of power and what is usually recognized as legitimate biomedical knowledge (Bryson & Stacey, 2012; Klawiter, 2008; Diedrich, 2007; Batt, 1994). This context of patient-centred knowledge creation demands further recognition in a bioethical framework. However, even if the standard story of breast cancer dominates public discourse on the disease and is the publicly recognized narrative of cancer, it is not the only narrative of breast cancer and it is not the final story of experiential cancer knowledge (see, for example, the Cancer’s Margins Interviews). That this project is able to discuss, specifically, “disruptive breast cancer narratives” is testament to a shifting public discourse of the disease and the writing of a different kind of cancer story. In exploring disruptive breast cancer narratives this project is positively informed by an interdisciplinary field of study which encompasses narrative and knowledge creation (Bryson & Stacey, 2013; Nelson, 2001, 2000; Segal, 2007b, 2005); public feelings and affective histories (Cvetkovich, 2007, 2003; Cvetkovich & Pellegrini, 2003; Berlant, 2004; Diedrich, 2007; Ahmed, 2004; Boler, 1999);
and the queering of gender, sexuality, and autobiographical acts (Stacey & Bryson, 2012; Bryson & Stacey, 2013; Jain, 2007a, 2007b). As an example that vivifies an archive of feelings, breast cancer narratives and expressions of anger are brought together in narrative form and debated in public discourse.

1.2 The Angry Breast Cancer Survivors

The image is striking. Three women, of differing ages and ethnicities, stand shoulder to shoulder, staring out intently at an imagined viewer. A glossy pink ribbon, thick like duct tape, covers each woman’s mouth. These women are, quite literally, muzzled by a pink ribbon. This image clearly depicts the pink ribbon of mainstream breast cancer awareness campaigns in an atypical fashion. For the pink ribbon has come to symbolise not only raising awareness, but also raising funds for breast cancer research in the hopes of finding “the cure” for the disease (Klawiter, 2008; King, 2006). It has also become synonymous with a certain culture of performing breast cancer patienthood and survivorship (King, 2006). Furthermore, this image suggests that the pink ribbon—and by extension its normative cultural values—is silencing, and violently so. Actually, this image disrupts any notion that the pink ribbon can be understood in apolitical terms.

Notably, this image accompanies an article, “The Angry Breast Cancer Survivors,” the title of which is spelled out in large, black font. Here, in the December 1, 2008 print edition of Maclean’s magazine, I first read “angry” and “breast cancer” in the same sentence—an unusual occurrence in mainstream media and for that reason alone noteworthy. Without a doubt, there is something positively disruptive about the title and image, something that then convinced me to read the article from start to finish, rather than skim it
quickly. “Women with post-treatment maladies find no one really wants to hear ‘downbeat’ stories” (Kingston, 2008, p. 71), the lead-in reads. “Unrealistic expectations of a buoyant recovery make it tough to get help with symptoms” (p. 71). This article provoked me to question mainstream media representations of breast cancer as both a disease and a culture, and I began to wonder how upbeat stories of “buoyant recovery” might affect women with a breast cancer diagnosis. Breast cancer culture, on the surface, appeared to be deeply invested in a culture of cheerfulness, an emotion women were then required to negotiate through diagnosis, treatment, and into life after cancer. There also seemed stringent expectations for how one should look and act as a woman with breast cancer, and other expectations for how one should behave and perform after cancer treatments as a breast cancer “survivor.”

Conversely, the sentiments expressed in “The Angry Breast Cancer Survivors”—of disappointment, pain, and anger—stand in contradistinction to typical depictions of breast cancer survivors and pink ribbon culture (Klawiter, 2008; King, 2006; Ehrenreich, 2001). However, the title and image of the Maclean’s article are slightly misleading, because what follows is a review of Emily Abel and Saskia Subramanian’s 2008 book After the Cure: The Untold Stories of Breast Cancer Survivors. Here, reporter Anne Kingston uses this text as a point of departure to question why so little attention is paid to women who experience negative symptoms after breast cancer treatment. Kingston questions why October’s Breast Cancer Awareness Month had come and gone with Abel and Subramanian’s recent publication receiving little to no media attention. She calls Abel and Subramanian’s After the Cure “groundbreaking,” (p. 71), pointing out that a book which highlights the otherwise untold stories of “women coping with life-altering, post-treatment maladies” (p. 71) runs counter to what Subramanian terms “celebratory breast cancer culture” (as cited in Kingston,
Kingston calls for further attention to be paid to narratives that disrupt breast cancer culture’s stock-in-trade “inspiring narratives of good health and spiritual rejuvenation” (p. 71). In just a few hundred words, Kingston’s article attempts to explore what it is about post-treatment complications that make it a narrative “no one really wants to hear about” (p. 71).

Kingston’s article perhaps knowingly scratches the surface of a much larger problematic embedded in the cultural politics of breast cancer; that is, a reluctance to endorse anything but celebratory, affirming, and positively transformative personal experiences of cancer (Klawiter, 2008; Diedrich, 2007; King, 2006; Herndl, 2006; Batt, 1994). As I will illustrate in my study of disruptive breast cancer narratives, “downbeat stories” not only serve a critical utility in illuminating the cancer experience, they also have the potential to create new knowledges. That they are even termed “downbeat”—and as such designated non-conforming—speaks to the limited availability of publicly acceptable ways to write about, or even experience, cancer (Segal, 2007a). Disruptive breast cancer narratives necessarily talk back to and resist the normative aspects of breast cancer culture. The public response to Kingston’s article—as evidenced by both the Letters to the Editor section of the print version of Maclean’s and in comments posted after the article was published online—was swift and copious. After the article was first posted online, up to the end of 2011, “The Angry Breast Cancer Survivors” had solicited over thirty comments from online readers. While many support the premise of the article (and by extension the book), online commentary did not function to leave the issue of post-treatment symptoms, nor their public reception, undisputed. A degree of public opposition to the article also provided the context for several women to remark on the difficulty of resisting pink ribbon culture and the expectation that they perform a certain brand or style of cancer patienthood and survivorship.
(King, 2006). That this dialogue, and public resistance to mainstream breast cancer culture, took place online also points to the often ephemeral nature of many acts of cultural disruption, and reinforces the need to engage with such public archives of knowledge and feeling.

Exemplary of this type of public backlash to “The Angry Breast Cancer Survivors,” someone writing under the name “Anna Keppa” took particular issue with the tone and content of Kingston’s article, as well as the editorial team at *Maclean’s* for publishing it. In this post, Keppa (2008) says:

I sense that the editors of this magazine do not understand the difference between being muzzled (the premise of the photos) and not being listened to. The difference is NOT subtle. Shame on you for not knowing that.

Millions of cancer patients rightly suspect they will never feel good again, but they don’t run to a magazine to bleat they are being “ignored” in favour of Happy Talk. The media are filled with “bad news”—it’s their stock in trade. If After the Cure wants to argue that it’s being ignored, it needs to make a case, not just trot out anecdotes.

Free clue: claiming “it’s because we’re women” or that people aren’t “aware” of breast cancer is threadbare to the point of being ridiculous.

Suck it up, ladies. You’re no different from anyone else.

Here’s hoping you all get well. Not blaming others for your plight is a good start.

(Msg 3).

For obvious reasons, this post generated heated online debate among readers. Whereas it might be read as a strident example of a certain attitude towards women with breast cancer,
there is also much here that could be seen to be corroborated, perhaps unwittingly, by mainstream or pink ribbon breast cancer culture. First, women with breast cancer simply “suck it up.” Which is to say they endure whatever cancer brings in its wake—first and foremost often debilitating treatments and perhaps later post-treatment symptoms—silently, stoically, and extremely privately. Women are not to “bleat” negatively about their experiences of breast cancer and, especially, they are not to call public attention to the often extremely difficult private reality of cancer. At base, what is expressed in these comments by Keppa is that there is no allowable public space for women to express negativity about their breast cancer experience, for to do so is to somehow “lash out” or “blame” others for one’s plight. There is a definitional difference between being “muzzled” and “not being listened to,” but in the context of a cultural politics where women are actively encouraged to tamp down negative feelings of anger, pain, and disappointment, the difference between being muzzled—prevented from free expression—and ignored—not being noticed or listened to—appears complicated, at best.

Anna Keppa’s online comments provoked several readers to respond to her directly. Writing under the name “Laurel McCartney” (2009), one such reader begins by saying “To Ms. Keppa, I normally wouldn’t waste any of my time left on this earth on comments like yours and I don’t know what prompted you to advise someone like me to suck it up.” McCartney concludes by saying:

I was the poster child for being responsible for my own recovery. I spent 2 years traveling around on behalf of the Canadian Cancer Society as a motivational speaker. I volunteered for fund raising, peer counselled other cancer warriors and their families. Bared my chest to the husbands of other women who wanted to see
what it would look like post surgery. I even got to be “Sunshine” girl for the Calgary Sun paper to try and debunk the myth that mastectomies would somehow render a woman sexless. I was and still am very positive. HOWEVER...people do not want to hear the other side of treatment. The stories expressed in “After The Cure” need to be told. We survivors have earned the right to tell ALL sides of our journey. Not just the “thank God we lived”. You have no idea what it cost then and what it continues to cost many of us to be able to say that. Shame on YOU. (Msg 4).

Here, Laurel McCartney explains that she did all that was expected of her and took personal responsibility for her own recovery, remained positive throughout treatments and remains positive into the present day in life after cancer. She was a “poster child” for the breast cancer awareness movement and in her various roles as motivational speaker for the Canadian Cancer Society, volunteer, fundraiser and peer counsellor she was an exemplary role model and survivor. Yet she too wants the disruptive stories in *After the Cure* to be publicly expressed. As she says, “all sides” of the cancer experience not only have a right to be told but should be told. Here, McCartney refuses to be admonished by the likes of Anna Keppa and redirects any burden of shame or guilt back at those who advocate that the difficult aspects of the cancer experience be censored out of publicly disseminated personal narratives.

Writing under the name “Wendy Raphael” (2008), another reader opens by saying: “It’s not clear where the source of Anna Keppa’s anger truly lies, but in her Comment, she unambiguously spews her venom towards the editors of Macleans [sic] as well as breast cancer patients.” But the problem, Raphael explains, “is that neither the medical community
nor the culture-at-large tolerates hearing about the lifelong serious and disabling conditions that are caused by the very cancer treatments purported to bring about a ‘cure.’” She argues:

Meanwhile, the culture at large, as the book rightly points out, is totally un receptive to hearing about the incurable, lifelong disabilities that result from conventional breast cancer treatments, all of which are, in some measure, highly toxic and/or injurious. The prevailing dismissive attitude seems to be, “hey, at least you’re still alive.” Ironically, Ms. Keppa’s Comment serves as a remarkably good example of this very attitude, however excessively acrimonious it may be. (Msg 7).

While Anna Keppa’s comments could be understood to be “excessively acrimonious,” as Raphael explains, they can also be read as remarkably representative of a certain “dismissive attitude” within the ranks of mainstream breast cancer culture. It is troubling to learn that, in Raphael’s estimation, because the medical community does not take post-treatment symptoms seriously it is poorly equipped to assist women with disabling maladies. She suggests that this lack of attention to post-treatment care manifests in part because the medical community, not unlike the breast cancer community, is focused on developing and administering the treatments that are to constitute “the cure,” and does not sufficiently factor in the potentially long-term consequences of such treatments.

Both Laurel McCartney and Wendy Raphael presume that Anna Keppa could not possibly have experienced breast cancer herself, for if she had she would not direct such vitriol at other breast cancer survivors. While this may be the case, such a situation is impossible to ascertain from Anna Keppa’s comments. This example highlights the complexity of performing and embodying breast cancer patienthood and survivorship. How to embody and perform breast cancer can be a site of conflict, not a place of intrinsically
shared values, because a diverse group of individuals are diagnosed and treated for breast cancer each year. The public perception of breast cancer is largely dependent on the sheer visibility of breast cancer survivors, while the power bestowed on the dominant performance and narrative of survivorship may function to marginalize other narratives, performances, and subjectivities within breast cancer culture. “Pam” (2009) writes of her observation of the prevailing performance of breast cancer survivorship and her own negotiation of the prescriptive cultural politics associated with this performance. She writes:

The only side of survivorship I have ever witnessed was that of positive, cheerful, fight-the-fight women—I’m not saying that’s a bad thing—I too put on “a happy face” (or “suck it up”) when needed. BUT.....after I [sic] awhile I started to feel very alone as a survivor—I started to wonder if I was the only one that had suffered from post treatment illnesses or effects brought about by the treatments—and really started to doubt myself as a survivor—afterall [sic] if I’m not happy and positive [sic] all the time what the heck is wrong with me—why can’t I be like those other women. Even though my own physicians would say “this is normal—you’ll get there” I still couldn’t quite figure out why I never ran into another survivor feeling the same way. (Msg 12).

Pam closes by saying, “What a gift to find out I’m not alone.” Here, Pam is encouraged to discover she need not remain isolated in her inability to perform only positive affects as a breast cancer survivor and that the complexity of emotion she experiences is not uncommon. In fact, she discovers there may be other ways to perform and that kinship and community may even be formed in resisting the dominant cultural and emotional public performance of breast cancer survivorship. Further, an affinity with others unwilling, or unable, to partake in
dominant pink ribbon culture may indeed become a site of potential self-empowerment, even political action, in the public sphere.

In the letters to the editor section of the December 29, 2008 print issue, Maclean’s reproduced the original image and published two letters under the subtitle “Pain Tolerance.” Both of the letters selected for publication applaud the article “The Angry Breast Cancer Survivors.” Sharon Wetselaar opens by saying, “Just read Anne Kingston’s story on post-cancer anger and don’t know what to say except: finally! Hallelujah!” (p. 7). “Your photo of the three women gagged with pink ribbons struck a resounding chord with me” (p. 7), writes Jennifer Smith. She adds, “If I had the money, I would reproduce this photo on billboards all over North America!” (p. 7). In their letters, both women detail how they struggled through cancer diagnoses and treatments only to later experience post-treatment symptoms which were not sufficiently addressed by their doctors nor validated by fellow survivors. Both women affirm that, like Pam, they did not feel as alone when they heard of other women’s experiences of post-treatment symptoms, they gained new knowledges of the disease and felt validated in learning that other women were also angry. Whereas in this project I do not seek to support or contest illness narrative scholarship centring on the supposition that telling one’s story has therapeutic value, and for this reason alone should be encouraged (Kleinman, 1988; Frank, 1995), I do want to acknowledge that the act of telling one’s story can function to encourage subcultural collectivity and affective solidarity. Highlighting the social nature of breast cancer patienthood and survivorship points to how collective negative emotional responses can serve to disrupt a discourse that seeks to individuate and “bright side” both illness and suffering (Ehrenreich, 2010; Diedrich, 2007; King, 2006).
While all of those who wrote online commentary and letters to the editor did so because they had something to say about “The Angry Breast Cancer Survivors,” the vast majority also revealed they were women with their own narrative of confronting breast cancer and pink ribbon culture in a less than “cheerful” manner. In writing their own stories, these women can be understood to contribute to a collective counternarrative of breast cancer. They actively engaged in disrupting the dominant discourse of disease where cancer ends, unproblematically, with the cure promised by biomedical treatments. The public response to “The Angry Breast Cancer Survivors” exemplifies how breast cancer narratives can function to disrupt the standard story of breast cancer and, in so doing, ignite difficult conversations in the public discourse of the disease. Here, personal stories of breast cancer do not function to end dialogue on the disease because they are rooted in personal experience; instead, they engender differently nuanced discussions. As these women actively mine their own affective histories, they write against the standard story of breast cancer disrupting the publicly acceptable performance of survivorship. In other words, these evocative stories truly can be understood as “an archive of feelings” (Cvetkovich, 2003). Importantly, in forming an archive of feelings, disruptive breast cancer narratives can be seen as countercultural public artifacts that shift and shape public discourses of the disease, an idea which I will take up and engage with throughout this project.

1.3 Gaps in Knowledge

This project aims to address three significant and interconnected gaps in the current state of research on the function, utility, and potential of public breast cancer narratives. First, although some research critiques the motivations, ethics, and knowledge claims of “the
standardized story of breast cancer” (Segal, 2007a; Herndl, 2006; Ehrenreich, 2001), which although dominates public discourse of the disease, it is not the first—and certainly will not be the last—narrative of experiential breast cancer knowledge. Although the dominant ideologies and normative beliefs often embedded in standardized storytelling of the breast cancer experience should be questioned and debated in the public realm, this project strongly cautions against dismissing and disparaging all public breast cancer narratives rooted in personal experience. Breast cancer narratives can be understood to be always, at least partially, constructed from potentially valuable, experiential knowledge of the disease. Rather than dismiss stories about cancer as only ever being able to contribute generic narratives to the project of patient-centred knowledge creation, this program of research seeks to query and collate these experiential knowledge claims. In it I will purposefully divert from examining easily recognizable iterations of the standard story of breast cancer, and will instead examine “disruptive” stories of breast cancer diagnosis and treatment in order to ascertain what knowledges are both shared and created through the public telling of these stories.

My aim is to situate disruptive breast cancer narratives as important counternarratives within breast cancer culture, as the sharing of personal stories remains an important feature of cultural world making focused on breast cancer (Knopf-Newman, 2004; Ehrenreich, 2001). Although previous research focuses on how the dominant narratives of breast cancer circulating through mainstream breast cancer culture have the potential to mislead, misinform (Segal 2007a; Ehrenreich, 2001), and even inflict harm on the vulnerable (Herndl, 2006), counternarratives of breast cancer often have an ethical orientation, and like all counternarratives constructed in response to master narratives, have the potential to repair the
narrative damage inflicted on identities and subjectivities (Nelson, 2001). Rather than deploying a disciplinary approach to the reading of public breast cancer narratives, in this project I will employ an interdisciplinary approach which aims to include feminist narrative bioethics (Scully, Baldwin-Ragaven & Fitzpatrick, 2010; Nelson, 2000; Wolf, 1996) in reading disruptive breast cancer narratives.

Second, mainstream breast cancer culture, or pink ribbon culture, is overtly identified with and by “cheerfulness” (Klawiter, 2008; King, 2006; Ehrenreich 2010, 2001), with concomitant calls to remain “positive” throughout diagnosis, treatment, and into life after cancer. This culture of emotion, dominant within mainstream breast cancer culture, can also be found in standardized narratives of breast cancer where the narrator, despite what may or may not have transpired over the course of diagnosis and treatments, retrospectively constructs a narrative that is not only cheerful, but publicly tells a uniformly “positive” account of enduring and healing from breast cancer (Herndl, 2006). So thorough is this “bright-siding” of disease within mainstream breast cancer culture, that some narratives can be read to move from cheerfulness into an even more problematic affective terrain where a positive embrace of the disease is endorsed (King, 2006; Ehrenreich, 2001). As a result, this program of research seeks to situate what mainstream breast cancer culture has lost in disallowing alternate affective responses to breast cancer within its culture. Whereas previous research has rightly identified the cultures of emotion that can be found within breast cancer culture as a social movement (Klawiter, 2008), this project seeks to further theorize, from feminist and queer frameworks, the problems with the “happiness,” “positive thinking” and “cheerfulness” found in mainstream breast cancer culture and in the standard narratives of breast cancer emerging from this culture.
By locating, identifying and analysing disruptive breast cancer narratives, this research will also situate a divergent culture of emotion—exemplified in and through disruptive breast cancer narratives—largely informed by “negative” affects. While less than positive accounts of breast cancer diagnosis and treatment are beginning to receive public attention and support (e.g., “The Angry Breast Cancer Survivors”), this project will not only draw attention to vivid examples of these types of narratives it will also illustrate the importance of public displays of anger, grief, and pain where cancer is concerned. In the public realm, these countercultural protests, performances, and narratives remain crucial in politicizing cultures of disease (Knopf-Newman, 2004; Diedrich, 2007), and in refuting a positive embrace of breast cancer as both a disease and a culture. This project will illustrate how “feminist anger” in particular can be understood as a key intervention in publicizing, politicizing, and disrupting mainstream breast cancer culture.

Third, in order to interrupt a discourse of illness narrative scholarship which can be understood to ascribe worth only to certain types of narratives, and therefore in and of itself forms a values-based discourse within illness narrative scholarship (Segal, 2005), this project further turns to theories of autobiographical performance and performativity in order to do more than situate certain public breast cancer narratives as “good” and others as “bad” (Langellier, 1999). To this end, a turn to performance studies and poststructuralist understandings of performativity works to provide a context whereby the performance of breast cancer survivorship, the predominant identity and cultural performance formed in relation to breast cancer (Klawiter, 2008; King, 2006; Ehrenreich, 2001), can be understood as a generic yet naturalised identity. From here, querying how gender, race, socioeconomic location and sexuality impact, from an intersectional perspective, this dominant performance
of breast cancer survivorship in the public realm has the potential to highlight how prescriptive and normative this identity can be. Further, a theoretical turn to an examination of performance and performativity encourages further discussions of the cultural politics of emotion and with attention to how specific emotions, such as anger, function as performative instances.

Rather than detracting from the material reality of the body, a turn to the theoretical implications of the performances and performativity of breast cancer requires that one take very seriously the experiential realities of those diagnosed, treated, and living with the disease and how this contributes to understandings of “the body in breast cancer” (Elhers & Krupar, 2012). As such, this project aims to contribute to recent scholarship on the impact of queer gender and sexuality on identities, knowledges, and performances formed in relation to breast cancer (Bryson & Stacey 2012; Jain 2007a, 2007b). Disruptive breast cancer narratives provide an exemplary site to query how the body functions in creating experiential knowledges formed in relation to minority subjectivities within breast cancer culture. These narratives illuminate how gender, race, and sexuality all affect different experiences of cancer, in part because both biomedicine and breast cancer culture are entrenched in normative expectations of whom breast cancer most often impacts. In addition, these disruptive breast cancer narratives query the larger problematic of what is known and unknown about breast cancer and how best to live through and after treatments for the disease. In these narratives, there is often a turn from the “individual body” to the “collective body,” as these cancer stories exemplify a paradigm shift in thinking through how best to prevent cancer in the first place (Potts, 2004).
1.4 Research Questions

The overarching queries that guide the research in this project can be distilled into three main research questions:

1) How do disruptive breast cancer narratives contribute to the creation of patient-centred and experiential knowledges? What are the issues and problematics disruptive breast cancer narratives prioritize, engage with, and enact in narrative form?

2) How do disruptive breast cancer narratives employ or perform anger in their narrative formation? And, in expressing anger, do disruptive breast cancer narratives signal a shift in the public discourse of breast cancer?

3) How do the cultural performances represented in and by disruptive breast cancer narratives function in relation to the context of mainstream breast cancer culture? In other words, do the performances and performativities of disruptive breast cancer narratives work to present alternate representations, embodiments and identities of breast cancer diagnosis, treatment, and life after cancer?

In this project’s research chapters, I examine a variety of published texts, films, and television sources. By using varying strategies and with different degrees of success, these disruptive narratives attempt to reframe the cultural politics of breast cancer culture by highlighting performances which divert from the governing culture of emotion, they address the politics of collective and individual cancer prevention and resist normative conceptions of gender, sexuality, and embodiment in order to expand the range of allowable performances of illness and identity within breast cancer culture. Because I investigate disruptive breast cancer narratives in relation to the wider breast cancer culture, I also seek to situate breast cancer theoretically as a cultural formation, in order to critique the dominant cultural
performance of survivorship. To best answer these queries I draw on an interdisciplinary framework. I first turn to literary criticism, and in particular specialists in autobiography and life writing attuned to how performance and performativity function in personal narratives, and imitate their attention to theoretically informed close readings of illness narratives. Additionally, my readings are informed by feminist approaches to narrative bioethics, and bioethics generally, focusing on where emotions and bodies can be situated as ethical orientations in breast cancer world-making. Always, my readings are informed by poststructuralist queer approaches to gender and sexuality. All of this manifests in an interdisciplinary approach to narrative studies and qualitative health research.

1.5 Description of Research Chapters

In Chapter Two, “Disruptive Breast Cancer Narratives and Interdisciplinary Health Studies: Engaging Relevant Scholarly Literatures,” I locate the interdisciplinary framework that informs this project and review the relevant scholarly literatures that best serve an investigation of public breast cancer narratives that manifest as disruptive of the mainstream. These interdisciplinary scholarly literatures include a range of topics: patient-centred knowledge creation; public feelings and the archiving of illness histories; body studies, and the querying of gender and sexuality in relation to breast cancer. I close this chapter by making a case for interdisciplinary health research and the potential of narrative inquiry in qualitative health studies generally, and in a project that investigates breast cancer narratives specifically.

In Chapter Three, “Theorizing Illness Narratives: Feminist Bioethics, Narrative Ethics and Disruptive Breast Cancer Narratives,” I outline my interdisciplinary theoretical approach
to disruptive breast cancer narratives. In this chapter, and throughout this project, I turn to feminist theory and, in particular, feminist bioethics and the narrative approaches to bioethics which have been positively informed by theoretical advances made in literary criticism. Here, I place narrative disruption in a context of historical and ongoing feminist interventions into dominant discourses, and situate biomedicine as a discourse that remains in need of the insights feminist bioethical inquiry might provide. The feminist perspective I am invested in advancing already recognizes that gender is but one instance of difference and that it is through intersectional analysis, where both privileges and oppressions become realities, that we can approach lived experiences and subjective cultural performances. In closing, I posit the potential counternarratives might have in healing subjectivities damaged by the master narratives told of both illness and breast cancer.

Throughout Chapter Four, “Feeling Angry in Cancerland: Rewriting Breast Cancer’s Cultural Script,” I engage with textual and cultural performances of anger. Here, I read three published narratives: Barbara Ehrenreich’s (2001) “Welcome to Cancerland,” Audre Lorde’s (1981) The Cancer Journals, and Kathlyn Conway’s (1997) Ordinary Life to ascertain how each author engages with feminist anger as a strategy to resist what she understands as the prescriptive cultural politics of breast cancer. I aim to provide a type of genealogy in order to show that Ehrenreich’s (2001) blistering critique of breast cancer culture has at least two antecedents, in The Cancer Journals and Ordinary Life. These texts provide a way of examining the problematics of feminist anger in the 1980s and 1990s, and especially feminist anger in relation to breast cancer culture. I end this chapter by turning to a more recent angry narrative, in the television drama The L Word (2006), and shift the focus from an explicitly feminist anger to a lesbian and potentially queerly articulated one.
In Chapter Five, “Claiming the Cancer Killjoy: Chasing the Cancer Answer and Crazy Sexy Cancer,” I read Wendy Mesley’s (2007) and Kris Karr’s (2006) documentaries as films that purport to disrupt the dominant discourse of breast cancer. Here, I explore a figure I call the “cancer killjoy,” borrowing Sara Ahmed’s (2010) explication of the “feminist killjoy.” The cancer killjoy is a troublemaker, a muckraker, and is not satisfied with a “business as usual” attitude where cancer is concerned. Mesley’s documentary engages with an environmentally motivated politics of cancer prevention, where grassroots activists urge industry and governments to find the root cause or causes of the disease. Mesley’s film frames the prevention of cancer as a collective project rather than an individual one. Karr’s documentary, on the other hand, while declaring itself to be a different kind of cancer story, inadvertently places cancer back into a normative, neoliberal discourse of individual responsibility. Karr’s personal story can be firmly situated within what Kathlyn Conway (2007) describes as a “triumph narrative,” whereby the individual, heroic narrative of overcoming illness becomes a prescription for others on how to live. Mesley’s film does not conclude on such a victorious endnote. Mesley survives breast cancer but she is angry that so many continue to be diagnosed, suffer, and die from cancer.

In Chapter Six, “Performing Elegiac Politics: Queering Gender, Sexuality and Breast Cancer,” I read Catherine Lord’s (2004) The Summer of Her Baldness in tandem with The L Word (2006). I begin with Eve Kosofsky Sedgwick’s (1993) personal essay “White Glasses,” looking at her claim that breast cancer itself inscribes gender in such a way that it requires the most normative performance of gender, sexuality and attitude in order to be understood as a woman. This chapter is guided by S. Lochlann Jain’s (2007b) conception of “elegiac politics” as a way to honour suffering, death, and dying in relation to cancer and industrial
capitalism. Here, I read Lord’s *The Summer of Her Baldness* as an example of elegiac politics as she mourns the loss of her hair and, by extension, stable notions of identity, her body, gender and sexuality. Because the third season of *The L Word* insists on making explicit a connection between a character undergoing diagnosis and treatment for breast cancer and a character transitioning from female to male, I question what this comparison might articulate about how queer gender and sexuality are formed not only in relation to breast cancer, but also in relation to industrial capitalism. Here, I turn to theoretical articulations of rage, specifically transgendered and transsexual rage as explicated by theorist Susan Stryker (1996).

In concluding this project in Chapter Seven, “Counternarratives: Performing Resistance, Patienthood and Narrative Repair,” I return to Barbara Ehrenreich’s (2001) “Welcome to Cancerland” as illustrating—as I have endeavoured to do throughout this project—that mainstream breast cancer culture has not only been resisted it has been disrupted by counternarratives of breast cancer rooted in experiential knowledge. These disruptive breast cancer narratives should be properly understood as doing important emotional, political, and cultural knowledge creation in the public discourse of the disease. Indeed, Ehrenreich’s counternarrative deliberately undertakes to do this kind of work, as it seeks to dislodge the power inherent in breast cancer culture and its dominant stories. Counternarratives, Hilde Lindemann Nelson (2001) argues, are exactly the kind of tools needed to repair the damage enacted through oppressive power systems. Here, I also explore how performing resistance, disruption, and patienthood all contribute to the troubling of master narratives, dominant rhetorics, and the standard story of breast cancer. Necessarily, I also reflect on my own experience of chronic illness and explore what narrative repair might
offer, not only for those diagnosed and treated for breast cancer, but for the many others diagnosed, and living with, complex experiences of illness.
2 Disruptive Breast Cancer Narratives and Interdisciplinary Health Studies: Engaging the Relevant Scholarly Literatures

2.1 Sharing Stories

In an era dominated by patriarchal medicine, the first edition of the feminist health classic *Our Bodies, Ourselves* (1971) exemplified how disseminating experiential knowledge by women for women about their bodies and lives could influence patient-centred knowledge creation and shift biomedical discourse (Potts, 2000; Boscoe et al., 2004). Through this instance of sharing stories, women were empowered to reconceptualise themselves, and other women, as the “true experts” on women’s bodies, health, and wellness (Boscoe et al., 2004).

Laura Potts (2000) argues that “privileged access to intimate and very personal stories of another’s life” was central to the formation of the Women’s Health Movement in the 1970s and 1980s, “as part of a conscious and radical determination to name and expose the socially constructed and punishable shamefulness of all aspects of female embodiment” (p. 99). Yet the seemingly incontestably personal aspect of another woman’s individual story “mired feminist debate in epistemological confusion” (Potts, 2000, p. 99). Importantly, the revolutionary aspect of consciousness-raising was that it granted political significance to personal experience and to the sharing of personal narratives. The aim was not to standardize women’s experiential stories but to learn from the lives of others and to expand one’s knowledge of the significance of lived experience (Potts, p. 100). Currently, Judy Z. Segal (2007a) argues that personal narratives perform a regulatory function in the public discourse on cancer; her essay, “Breast Cancer Narratives as Public Rhetoric: Genre Itself and the Maintenance of Ignorance” is a critical response to the genre of personal narrative and the most strident critique of breast cancer narratives published in an academic journal. Here,
Segal asserts that breast cancer narratives function as one way to maintain, and even produce, ignorance about the disease. As a result, in this chapter I trace why I remain unconvinced by the supposition that breast cancer narratives rooted in personal experience are intrinsically unable to advance public dialogue and discourse about the disease. I turn to scholarly literature which examines the role of feelings in the public sphere and how affective illness histories and archives of feeling can be expressed through stories such as disruptive breast cancer narratives. Moreover, I consider how the body, including explorations of gender and sexuality, informs this type of experiential storytelling and why this particular knowledge creation is both significant and poignant. I close this chapter by emphasizing the power personal narratives continue to hold in informing and illuminating biomedical discourse.

2.2 Public Breast Cancer Narratives and Patient-Centred Knowledge Creation

Segal (2007a) maintains that “the standard story” of the breast cancer survivor is the dominant one in public discourse and this narrative contains easily recognizable features (p. 4). The standard story most often begins with the discovery of a breast lump, hence “the cancer story begins with the appearance of unwanted tissue in an individual body” (Segal, 2000, p. 4). It also typically concludes with the author sharing what lessons cancer has imparted. For example, in a recent issue of Beyond, a magazine by and for women with breast cancer, the author of such a standard story says: “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, as cited in Segal, 2007a, p. 4). Conventionally, as Segal notes, the standard story has a happy ending, if only because the author has survived breast cancer long enough to write her narrative. But
“the standard breast cancer story does not emerge in a vacuum and it is not innocent” (p. 6), as Segal rightly argues. “All narratives” in truth “have a political function in that they produce a certain way of seeing the world” (Langellier, 1989, p. 271). Furthermore, the standard story contains a “prescriptive coda,” which is: “Be like me” (p. 4). Thus, Segal asks, “what are the warrants for resisting, as I have resisted, the narrative that has emerged as the standard story of the breast cancer ‘survivor’?” (p. 4). Whereas there are several good reasons to resist the standard story, Segal (2007a) also argues that personal narratives can end dialogue on breast cancer because they function as a “conversational trump card” (p. 18). “That is one way of viewing popular discourse on breast cancer,” she says, “as a series of narrative conversational turns, with little means of advancing the dialogue” (p. 18).

Segal (2007a) rightly cautions that “while the standard breast cancer story has variations, its formula is so compelling that, often, without the will or even the knowledge of individual narrators the story writes itself” (p. 10). She stresses also that “no woman sets out to tell a story that is not humane or generous or inclusive” (p. 10). Segal is convincing when she argues that “people do not fashion their narratives out of just the events of their lives,” because “narratives are structured using available narrative knowledge” (p. 6). If I suggest that “personal narrative” and “breast cancer narrative” are not necessarily one in the same, I am not making a concomitant call for a repudiation of the personal aspects of a breast cancer narrative. For what is breast cancer if not an extremely “personal” life event, even if a cancer diagnosis can also function to depersonalise individuals through the various processes of medicalization? Perhaps breast cancer, as a disease and a culture, is best understood through collectivity and contingency, but it is also very personally felt, expressed, and performed. Surely, narratives written out of this experience will necessarily, and productively, include
elements of experiential knowledge, and the authors of breast cancer narratives deploy “experience” as a key narrative strategy in the “constitutive process of autobiographical subjectivity” (Smith & Watson, 1998, p. 15). But they also employ other strategies, such as engagement with memory, identity, embodiment, and agency (pp. 15-48).

To be sure, personal narratives have been taken up by people of colour, feminists, queer people—and for that matter, queer feminists of colour—as well as others traditionally excluded from hegemonic centres of power. “Personal narrative situates us not only among marginalized and muted experiences but also among the mundane communication practices of ordinary people” (Langellier, 1999, p. 126). In recent decades the multifarious “personal narrative” has been taken up with enthusiasm by both writers and readers. However, Segal (2007a) argues that “these homogenous stories for which the public seemingly has an endless appetite, suppress or replace other stories, and personal narratives suppress or replace other genres in which breast cancer might be queried and explored” (p. 4). A decade and a half earlier, feminist literary critic Linda S. Kauffman (1992) warned “there is something fatally alluring about personal testimony” (p. 1158). Moreover, Kauffman’s “The Long Goodbye: Against Personal Testimony or an Infant Grifter Grows Up”—a circuitous argument against personal narrative that makes use of personal history in order to make an argument against personal testimony—is, at base, an argument against the bourgeois individualism historically associated with personal narrative in its many manifestations. As Sidonie Smith (1993) stresses, “all kinds of subjects excluded from the status of bourgeois individual have also engaged in autobiographical acts—colonized and enslaved people, working-class men and women, bourgeois women, members of variously oppressed groups” (p. 398).
These stories, Smith reminds us, bring to life writing what bell hooks has called “experientially based history” (as cited in Smith, 1993, p. 398), where individuals create identities through telling a personal history (p. 398). Kauffman (1992) also concedes that “one can obviously use the personal voice without forgetting history, society, politics” (p. 1159). “More difficult to resist,” she argues, “is the temptation to view the personal as inherently paradigmatic, the individual life story as coherent, unified, orally inspiring” (p. 1159). She minces no words when she says: “Writing about yourself does notliberate you, it just shows how ingrained the ideology of freedom through self-expression is in our thinking” (p. 1164). She points out that whereas personal testimony can be moving and persuasive, it is not an “infinitely inexhaustible genre” (p. 1168), yet neither the reading nor the writing of personal narrative is a simple act. “Reading personal narrative,” Smith (1993) says, “we find ourselves immersed in complex issues of representation, ideology, history, identity and politics as they bear on subjectivity” (p. 393).

Conversely, while Segal (2007a) stresses that she is “not against narrative” (p. 17), she also argues that “personal narrative is itself a pink genre; it is so welcome in part because it is unthreatening—unlike, for example, the genre of the protest rally or the diatribe” (p. 17). This can be understood as a rather reductive view of personal narrative, since breast cancer narratives can be understood to incorporate aspects of protest and denunciation in their storylines (Knopf-Newman, 2004; Lorde, 1980). While Segal (2007a) argues that personal narrative “is an egocentric genre: it honours the individual and neglects the collective” (p. 17), breast cancer narratives do not necessarily adopt this individualistic perspective (e.g., Chasing the Cancer Answer). That said, Segal further cautions that because personal narratives are deemed sacrosanct they function in a sphere “protected from criticism” (p. 17).
Therefore, Segal asks, “Who continues to be critical in the face of the personal cancer story?” (p. 17), an important question to be sure. Yet Kristin Langellier (1999) persuasively argues that if the terms of debate are limited to either “celebratory” or “suspicious” positions (p. 129) a conversation on the consequences of personal narrative are not able to move forward.

For Langellier (1999) “a celebratory vision emphasizes the hopeful project of personal narrative: its human agency and potential for self-transformation through re-storying; its immediacy, emotionality, and embeddedness in experience, and its invitation to empathy and shunning of elitists and experts” (p. 129). From this perspective, personal narrative has the ability to “educate, empower, and emancipate” (p. 129). In opposition, “a suspicious view raises concerns over personal narrative’s confessions and self-indulgences; its misleading consolations and diversions from material conditions; its inscription of experience within existing structures of domination” (p. 129). Here, “personal narrative can individualize and overpersonalize; it can normalize, naturalize, and moralize” (p. 129).

Nonetheless, as Langellier argues, “telling one’s story as a personal narrative always carries risk, existential and political: on the double edge and fine line between hegemony and resistance, between recuperation and transgression” (p. 130). “Disclosure” in personal narrative, she says, “may increase as well as diminish domination” (p. 130).

Segal (2007a) asks, “What are the questions to which personal narratives are the answers?” (p. 16). She believes that the most obvious question personal narratives answer is: “What is it like to have breast cancer?” (p. 16). She is concerned that breast cancer narratives, cumulatively, “constitute an answer to a larger question: ‘How shall one be ill?’” (p. 16). Here, Segal uses the concept of “agnotology”—“the study of the cultural production of ignorance” (p. 4)—as a conceptual framework around which to organize her queries of breast
cancer narratives. She argues that serious engagement with the overarching question of “How to be ill?” is especially problematic if breast cancer narratives espousing “the standard story” claim to already have the answer. Therefore, “serious engagement with the question of how to be ill has been preempted by texts that make it seem already to have been answered” (p. 16). Segal maintains that “as long as the personal narrative dominates public discourse on breast cancer, some questions will be suppressed, even silenced, and a degree of ignorance about the disease will be maintained” (p. 17). As I argue here, and throughout this project, breast cancer narratives need not function to end dialogue on the disease simply because these stories are rooted in personal experience. Undeniably, breast cancer narratives can also offer a window into patient experience by illuminating an embodied approach to breast cancer and presenting new patient-centred knowledges of the disease. This endeavour can be conceptualised as an activist archive of personal stories to which many diagnosed with breast cancer, Segal included, seem keen to contribute.

In 2010 Segal wrote an opinion piece for *The Vancouver Sun*. Published on April 1, the first day of Cancer Awareness Month, the title of her article declares “Cancer Isn’t the Best Thing that Ever Happened to Me.” Here, writing for a general audience, Segal reveals that she was recently diagnosed and treated for breast cancer. She speaks to her previously published academic article saying that it was generally well received—except by two women who wrote to say: “‘If you haven’t had breast cancer, you can’t know what it’s like” (p. A15). Segal reports that this “objection was one I took seriously” (p. A15). She says, “I was chastened a bit” (p. A15) but then jokes, “I had moments of wondering whether, if I were ever unlucky enough to receive a breast cancer diagnosis, I might go to bed one night and wake up as someone with a sudden taste for pink T-shirts and group athleticism” (p. A15).
Segal reports that while she did have the unfortunate experience of receiving a cancer diagnosis, she is happy to report that she remains pretty much herself—save for the fact the she understands even better “how the whole narrative/values thing really works” (p. A15).

Segal (2010) describes how thankful she was for the generous support she received from family and friends during cancer treatment, but says there was also “a strong element of something else” (p. A15) in the emails and cards she received. “Over and over again, I was praised for being strong and positive, courageous and combative…But this praise was offered mostly in the absence of evidence that I was really any of those things” (p. A15).

Segal explains that it was not that she was being told she must be strong, instead, she argues, it was that she was implicitly steered away from other ways of being. Segal proposes an alternate way of interpreting of Cancer Awareness Month. She proposes that we need to develop an “awareness of the way we talk about the disease—especially breast cancer, which has acquired a special status in the world of illness” (p. A15). “The things we say about breast cancer have become so generic and so predictable that there are, increasingly, limits to what’s sayable about breast cancer at all, especially by the people who have it” (p. A15).

Here she describes breast cancer’s standard story as: “I found a lump; I was scared; I stayed positive and fought; I recovered; now I am a better person; in some ways, cancer is the best thing that ever happened to me” (p. A15). She finds this problematic—not because she thinks it false or lacking in heart, but because it has become redundant, coercive and “unwaveringly self-righteous” (p. A15). “How many cancer stories have you read,” she asks, “that say exactly the same things?” (p. A15). Adding, “if, as a person with cancer, you violate the code of optimism, or if cancer somehow failed to improve you, you’d better be quiet” (p. A15).

She argues:
An unconventional breast-cancer story gets harder and harder, under existing conditions, to tell. Most people don’t want to hear from a breast cancer patient who is angry—not at the disease itself, but at the terms of the club of which she is suddenly a member. (p. A15)

In all of her writing on breast cancer narratives, Segal calls for a different kind of cancer story. Without a doubt, she calls for breast cancer narratives that dare to disrupt the tropes of the standard story. In several instances, breast cancer narratives rooted in experiential knowledge have already answered this call, as Knopf-Newman (2004) has successfully highlighted in her own scholarly work.

Marcy Jane Knopf-Newman (2004) chronicles a history of women’s writing on breast cancer in the United States, arguing that select autobiographical narratives have not only changed public perception of the disease but also public policy and medical practices. She examines the autobiographical writings of Rachel Carson, Betty Ford, Rose Kushner, and Audre Lorde, framing these narratives within a larger historical context of feminist interventions into women’s health and wellbeing. Carson, Ford, Kushner and Lorde’s published narratives, Knopf-Newman argues, “galvanized women to take a more active role in their healthcare…which eventually mobilized women to overcome the barriers to women’s agency in the medical system” (p. 5). The crux of Knopf-Newman’s argument is that when breast cancer narratives transcend the private realm of the author they have the potential to transform the political sphere by inciting action. She highlights the writing of women who “wrote about their breast cancer and resisted the impulse to contain breast cancer in an apolitical, private space, for doing so contributes to blaming the victim, which saturates the mass-media representations of the disease” (p. 23). “Illustrating some of the ways in which
women’s public writing has helped to redirect the impetus to blame women,” she says, “I look for answers in the larger systemic and institutional forces that they wrestled with” (p. 23). For example, Knopf-Newman is extremely appreciative of Audre Lorde’s writing, namely *The Cancer Journals*, saying that she uses Lorde’s “work as a model for transforming the way we think about breast cancer” (p. 26). She asserts that Lorde’s “critique of the breast cancer establishment provides us with the most complex way of examining the intersection of the personal—race, class, gender, sexuality—and the political—the environmental causes of the disease” (p. 26).

Here, Knopf-Newman (2004) illustrates how breast cancer narratives can be politically insistent in the public realm, asserting that not all authors prescriptively tell iterations of the standard story, and that these stories can function to politicize cultural studies of disease by connecting autobiographical literature to political action in meaningful ways. Knopf-Newman describes her project as “a call to politicize cultural studies of disease by linking the literary to political struggles, particularly the struggle to determine the relationship between cancer and the environment” (p. 26). Like Knopf-Newman, Lisa Diedrich (2007) notes the emergence of the politicized patient by the end of the twentieth century and a new genre of writing—the politicized patient’s counternarrative to the written medical charts and case histories of biomedical discourse. Diedrich stresses that in her readings of breast cancer narratives she pays attention to how the body, knowledge, and language are all potentially made politically salient through the manifestation of illness. Importantly, Diedrich does not repudiate the personal aspects of breast cancer narratives in her analysis; instead, she employs the distinction between “affective” and “effective” histories as a theoretical way to read these public narratives of illness.
Diedrich (2007) names Susan Sontag, Audre Lorde, and Eve Sedgwick as writer-activists and examines *Illness as Metaphor* (Sontag, 1990), *The Cancer Journals* (Lorde 1981), and “White Glasses” (Sedgwick, 1993) as examples of politicizing patienthood. She argues that Sontag does not appear to offer a personal response, or “affective history,” in relation to breast cancer because she elects instead to tell an “effective history,” but her narrative can also be read, paradoxically, as “a depersonalized personal narrative of illness” (p. 26). Diedrich argues that “Sontag depersonalises, and also de-heroicizes, her response to illness in order to, in her view, offer a strategy to others that she believes is most *effective*” (p. 26). Conversely, Lorde and Sedgwick write breast cancer narratives that narrate both “affective” and “effective” histories. Lorde, Diedrich says, is “an exemplary writer-activist who transformed the silence surrounding breast cancer through language and action” (p. 26). Sedgwick, like Sontag and Lorde, wants to challenge “the hegemonic sick role and its passively heroic mode of being ill” (p. 27). Sedgwick does this, Diedrich argues, “by making use of her theoretical and political concept of ‘queer performativity’ in relation to her personal experience of breast cancer” (p. 27). Diedrich’s interdisciplinary study of illness narratives—with its attention to language, politics and culture—provides a particularly good example of how and why breast cancer narratives should be read from an interdisciplinary perspective. Interdisciplinary study reveals that disruptive breast cancer narratives highlight not only autobiographical acts and performances, but also the affective dimensions of the public sphere and how these personal stories of illness have the potential to form, individually and collectively, significant archives of feeling.
2.3 Public Feelings, Affective Illness Histories and Archiving Feelings

As the name suggests, the academics, artists and activists that contribute to the collective known as “Public Feelings” aim to explore the role of emotion in public life. The project emerged in postmillennial U.S.A. out of scholarly conversation on the topic of “Feminism Unfinished,” where discussion centered on how feminism could be positioned to have more impact in the public sphere (Berlant, 2004; Cvetkovich, 2003). Public Feelings went on to inspire regional cells such as those in Chicago, New York, and Austin and collectively form what could be understood as a national, interdisciplinary “feel tank” rather than a “think tank.” Public Feelings has undertaken to examine the emotional dynamics of public life in postmillennial America rather than focus on a strictly sociopolitical analysis of the same geopolitical events that continue to reverberate through the public sphere in contemporary North America. For, as Lauren Berlant is reported to have said, the public sphere is not “rational,” it is “rhetorical” (as cited in Staiger, Cvetkovich & Reynolds, 2010, p. 2). Taking a cue from the important theoretical and methodological work done by Public Feelings, my project understands breast cancer as both a disease and an important cultural formation with a large affective presence in the public sphere. Because I seek to explore how breast cancer narratives inform, as well as form, archives of feeling in the public sphere through the narration of experiential knowledge, a brief turn to queer and feminist scholarship on public life and emotion is necessary.

To be sure, both feminist and queer scholarship have exposed how the division of life into private and public realms has served to undermine the social, cultural and political actions—not to mention knowledge claims—of women and members of the queer community (Staiger, Cvetkovich & Reynolds, 2010, p. 1). Further, a discourse that
understands emotion as belonging properly to private worlds rather than public spheres has functioned to undermine the distinctly public acts of both women and queer activists (Boler, 1999). Certainly, particular emotions continue to be regulated in the public sphere, especially when the performing bodies are female, queer or racialized others (Ahmed, 2004; Jaggar, 1996). That said, Ann Cvetkovich and Ann Pellegrini (2003) ask if the realm of “public sentiments” continues to be especially fraught for women because of a sociocultural and Western historical association that connects “femininity” to “emotionality.” They rightly wonder if, in the present day, certain performances of public emotion are further disparaged because “feeling” continues to be negatively associated with “the feminine.” Cvetkovich and Pellegrini remind us that “femininity” and “sentimentality” have been connected in such a way that certain feelings are publicly interpreted as excessive, even insincere, and best expressed in private, if at all. The sphere of “women” and “public feelings” is a fraught terrain for many to enter, and especially so in a context that is as highly charged as that of breast cancer discourse. For if emotion is deemed to be essentially “feminine”—and lesser than “rationality”—how might women perform emotion in the public sphere in ways that are legible and not only receive public attention but also inspire public dialogue and action?

What Feel Tank Chicago has termed “political depression” refers to a sense that traditional acts of participation in the political sphere such as voting, protest, and critical analysis are done with a pervading sense that they actually fail to produce social change. Not only do these acts fail to make one feel better about the political process, they also fail to make one feel better individually and subjectively about participation in the public sphere (Berlant, 2004). Conversely, when Feel Tank Chicago organized an “International Day of the Politically Depressed” participants were encouraged to manifest their “political
depression,” to arrive at the rally dressed in bathrobes and slippers and broadcast the campaign slogan “Depressed? It Might Be Political!” Here, a necessary critical and performative move is employed in order to depathologize negative affects through a public performance. In this example, positing that “depression” can be used as a resource for public action, “political depression” then becomes a site of community formation and publicity (Cvetkovich, 2007). Instead of conceptualizing negative affects as instances of turning away from engagement and participation in public life, negative affects might instead be understood to function as a manner of vital attachment (Berlant, 2004). What is understood as “negativity” is not necessarily the manifestation of disengagement from public life, a kind of listless apathy, but can be reconceptualised as a kind of political consciousness. Negative affects have the potential to ignite critical engagement within the sphere of public feelings in ways that can be theoretical and theatrical, personal and performative, embodied and cerebral, as I will illustrate in examining the disruptive element of anger in the breast cancer narratives discussed throughout this project. It is immanently important to connect scholarship on public feelings to literature that explores the affective work illness narratives do as well as, more broadly, to literature which reinvigorates theoretical discussions of emotion by approaching this topic from feminist and queer perspectives.

Throughout *Treatments* Lisa Diedrich (2007) speaks to the cultural, political and affective work illness narratives do in the public sphere, considering what illness narratives do for those who write and read them, and the literary, medical, and cultural institutions these stories are absorbed into or stay apart from (p. vii). She considers the various ways illness narratives describe individual illness experiences and the ways illnesses also become cultural and political events (p. xvii). One of Diedrich’s central arguments is that “illness narratives
are both effective and affective histories; that is, histories that are attentive both to the rhetorics and practices of politics as well as to the poetics and practices of suffering” (p. ix). Here, Diedrich employs Foucault’s articulation of “effective history” which opposes any idea of historical objectivity, focusing instead on historical work that has political significance and will have utility in the future (p. xvii). If Foucault’s “effective history” is essential in demonstrating “discontinuity and rupture at the sociocultural level,” as history is always inscribed on individual bodies, “illness narratives also demonstrate discontinuity and rupture at the subjective and intersubjective level” (Diedrich, 2007, p. xviii). Diedrich argues that in exploring illness narratives it is necessary to take seriously the “affective” as well as “effective” aspects of such stories,

in order to grasp the ways in which the breakdown of the body that occurs in illnesses provides a phenomenological reduction of sorts that allows one to look anew upon that which one has formerly taken for granted, in terms of one’s relationship to the world, to others, and to the self. (p. xviii)

Affective histories, then, respond to effective histories and act as a necessary intervention in order to consider the rupture of subjective and intersubjective experience as evoked by illness.

In turning to “affect” in a poststructuralist project such as Treatments Diedrich engages with current interdisciplinary interest in returning to emotion in feminist and queer theorizing. Affect, as an already important theoretical category in psychoanalytic theory, has more recently been taken up throughout cultural studies. What we name things is vitally important, and scholars such as Kathleen Woodward, Ann Cvetkovich, and Sara Ahmed work with “affect,” but also use the synonyms “emotion” and/or “feeling.” In the same way, I am especially interested in how affects, emotions and/or feelings are both performed through, and
become performative, in illness narratives that take the form of disruptive breast cancer narratives. The notable “affective turn” in feminist scholarship, “be it under the banner of affect, emotion, passion or feeling, involves encountering many turns: to embodiment, to phenomenology, to Darwin, to biology, to history, to politics” (Koivunen, 2009, p. 22), as well as to the body, health, and disease, as I will explore in this project.

Anu Koivunen (2009) traces contemporary queer and feminist scholarly interest in affect, viewing it “as a further moment in the historical process of critical self-reflection, as one further reconceptualization of the subject of feminism” (p. 11). She also maps the turn to affect as a consequence of thinking through and of the body, which is particularly important not only in illness narratives generally, but breast cancer narratives specifically. As Koivunen argues, “feminist scholars have turned to the question of affect and the topic of affectivity in search of a new critical vocabulary for investigating and conceptualizing the subject of feminism as embodied, located and relational” (p. 8). It continues to be important to note “how embedded in particular emotion cultures the political language of feminism and other social movements are” (p. 19). Cultures of emotion have the potential to be normalizing, when in order to be recognized and understood one must emote “properly.” Samantha King (2006) describes such a problematic in breast cancer culture as the “tyranny of cheerfulness” (p. 101), where the performance of hope and happiness is not so subtly demanded of those diagnosed and treated for breast cancer. As Maren Klawiter (2008) explains, in framing breast cancer culture as a complex social movement made up of several cultures of action, these cultures of action are in turn guided by cultures of emotion (p. 47). Whereas in the culture of “early detection” a hopeful, celebratory attitude prevailed, in the culture of “patient empowerment” public anger was expressed but compassionate private support was available
for women living with cancer, and in the culture of “cancer prevention” unmitigated anger was directed towards the “cancer industry” (p. 47).

In this way, Sara Ahmed’s aim in *The Cultural Politics of Emotion* (2004) is not to answer “What emotions are” but rather to illustrate “What emotions do.” In answering the latter question Ahmed does not offer a singular theory of emotion, nor does she offer one account of the work that emotions do (p. 4). Instead, she maps “how emotions circulate between bodies, examining how they ‘stick’ as well as move” (p. 4). Here, she conceptualises “affective economies” where feelings are produced through circulation (p. 8). She stresses that circulation “allows us to think about the ‘sociality’ of emotion” (p. 8). Ahmed’s conception of the sociality of emotion disrupts a psychological understanding where emotion is based on a presumption of interiority. As Ahmed explains, in this model of emotion “I have feelings and they are mine” (p. 8); thus, she terms this the “inside out” model. In critiquing it, Ahmed contributes to work in cultural studies arguing that emotions are best understood not simply as psychological states but as social and cultural practices (p. 9). In this way, I contend that the emotions of breast cancer narratives can also be understood as performances, and read in performative terms as these emotions are expressed in the public sphere.

Ahmed (2004) is cautious towards a rigid sociological understanding of emotion, the “outside in” model, where emotions function as social forces and “the individual is no longer the origin of feeling” (p. 9). She stresses that this conception of the sociality of emotions can take a similar form to the psychological model, though divergent in orientation. Here, she says, the “inside out” model has simply become “outside in” (p. 9). The problem is that both models “assume the objectivity of the very distinction between inside and outside, the
individual and the social, and the ‘me’ and the ‘we’” (p. 9). “Rather than emotions being understood as coming from within and moving outwards, emotions are assumed to come from without and move inward” (p. 9). As Ahmed stresses, the “outside in” model is crucial in “crowd psychology,” “where it is assumed that the crowd has feelings, and that the individual gets drawn into the crowd by feeling the crowd’s feelings as its own” (p. 9). Ahmed offers a different understanding of the sociality of emotion by suggesting that it should be thought of as relational. “In my model of sociality of emotions,” she says, “I suggest that emotions create the very effect of the surfaces and boundaries that allow us to distinguish an inside and an outside in the first place” (p. 10). Emotions are not, simplistically, something we have individually or collectively. Instead, “it is through emotions, or how we respond to objects and others, that surfaces or boundaries are made” (p. 10). Therefore, Ahmed says, “emotions are not ‘in’ either the individual or the social, but produce the very surfaces and boundaries that allow the individual and the social to be delineated as if they are objects” (p. 10).

In addition, and of particular importance to my project, is Ahmed’s (2004) assertion that feminist and queer theorists have illustrated how emotions matter in a political sense, because feelings show us how power shapes bodies and worlds (p. 12). In this way, then, a model of the sociality of emotion reveals how we “feel our way” (p. 12). In situating how we feel our way publicly, emotion is theorized as “a form of cultural politics or world making” (p. 12). In Ahmed’s work “emotions are a site of embodied meaning-making and social ordering, but even more importantly they are the process in which very boundaries of individuals and communities are drawn and redrawn” (Koivunen, 2009, p. 14). Ahmed’s conception of what emotions have the potential to do—in terms of individuating, connecting
and world making—has motivated my own thinking on how to situate the importance of emotion has in breast cancer narratives and how these narratives, collectively and individually, form archives of feeling. Ann Cvetkovich’s foundational text *An Archive of Feelings* (2003) provides a representative example of how “affective experience can provide the basis for new cultures” (p. 7). Here, Cvetkovich turns to cultural memories of national trauma history from the “unabashedly minoritarian perspective of lesbian cultures,” which “serves as a point of entry into a vast archive of feelings” (p. 7). While the structure of the book and its materials are diffuse, it is organized “as ‘an archive of feelings,’ an exploration of cultural texts as repositories of feelings and emotions, which are encoded not only in the content of the texts themselves but in the practices that surround their production and reception” (p. 7). Cvetkovich’s goal is to illustrate how affect, and examples of trauma, can provide a foundation for public cultures (p. 10). “This argument,” she explains, “entails a reconsideration of conventional distinctions between political and emotional life as well as between political and therapeutic cultures” (p. 10). It is important, Cvetkovich stresses, to incorporate affective life into conceptions of citizenship and to “recognize that these affective forms of citizenship may fall outside the institutional practices that we customarily associate with the concept of citizenship” (p. 11). This conception of citizenship, as a form of affective belonging, can bind participants in a social and political economy of feeling; indeed, their negative feelings of disappointment, pain and anger are not unlike those expressed by angry breast cancer patients and survivors.

Cvetkovich’s (2003) *An Archive of Feelings* can be understood to produce an archive as much as it also seeks to analyse the problems and problematics of forming one (p. 8). In forming an alternative archive of queer trauma, Cvetkovich turns to multiple genres
including the novel, poem, interview, video, film, photography, autobiographical writing, and performance. Cvetkovich explains that in forming this archive of feelings she hopes to “forge methodologies for the documentation and examination of the structures of affect that constitute cultural experience and serve as the foundation for public cultures” (p. 11). Her approach to genre is inclusive and thus includes a broad range of texts and artifacts, which “enables attention to how publics are formed in and through cultural archives” (p. 9). An archive of feeling, in significant ways, also functions to “create practices of mourning” (Cvetkovich, 2003, p. 269). Whereas breast cancer culture can be understood to disavow death (Jain, 2007a, 2007b)—by emphasising the potential for the return of good health after cancer treatments, of better and more tolerable cancer treatments, and by accentuating positive ways to live with cancer (King, 2006)—women do die from the disease and there must be a space for public feelings of despair and sadness. If public memorials to the lives lost to cancer are not possible in the current historical moment, then ephemeral archives of mourning are not only possible, but like the archive formed in and around angry breast cancer stories, are often brought into existence through counternarratives and subcultural collectivity. To this end, disruptive breast cancer narratives which explicitly explore the body—as being emotive, experiential, and material—significantly inform and shape the formation of this archive of feeling.

2.4 The Body, Gender, Sexuality and Disruptive Breast Cancer Narratives

Rita Charon (2006) makes important connections between narrativity, relation, and the body as it relates to poststructuralist conceptions of the self and postmodern understandings of autobiography and illness. She argues that the recognizing and becoming of self “unfolds in
narrative language” and “takes account of the body” (p. 73) while in relational attention to others. These elements are significant in understanding illness and medicine as performative events inextricable from narrative and narrativity. “Narrativity,” Charon argues, “is a hallmark of postmodern theorizing about autobiography, that is, that identity is both declared and created with narrative” (p. 73). If there were once negative associations with the term “storyteller,” now “to be called a storyteller means not that the teller is telling lies but that the teller is creating self” (p. 73). Autobiographical narratives are not created in autonomous isolation; rather, they are constructed in relation to and with others, as the body “insists on intersubjective relation because bodies have surface, needing contact” (Charon, p. 76). Subjectivities “do not become—or create—themselves in autonomous and deracinated acts of will but instead develop over time in concert with others” (p. 75). Moreover, Charon argues, “all roads in contemporary autobiographical theory lead to the body” (p. 76).

Narratives of illness and disease—of self, of breast cancer—speak to the physical and emotional body in visceral and meaningful ways. For the self both has, and is, a body (Charon, p. 76). “With the body in view,” Charon argues, “autobiography cannot claim immortality but must succumb to temporality” (p. 76). Jackie Stacey and Mary Bryson (2012) argue that as much as cancer warps time in particular ways, it also, “warps the temporality of the body” by twisting “our temporal perceptions of our own bodies, which, however illusory, anchored the modern subject in anxious desire for certainty and predictability” (p. 7). This warped nature of both time and body is bound to have an impact on the ways in which breast cancer narratives are told and written. Paradoxically, in the postmodern moment, specific attention to “the body” in breast cancer remains a marginalized aspect of the critical literature, as noted in a recent special issue entitled “The Body in Breast
Cancer” (Ehlers & Krupar, 2012, p. 2). Ehlers and Krupar argue that theoretical literature “too often fails to account for the complexities of bodily experience, bodily materiality, and the ways subjects contend with the threat of cancer at the corporeal level” (p. 2). In response, authors in this issue of Social Semiotics insist “on foregrounding the body as the material site of breast cancer,” rather than contributing to a broader logic that dismisses bodily knowledges or even absents the body (Ehlers & Krupar, p. 2). “These bodies themselves—bodies with and bearing the traces of breast cancer and its accompanying technologies—incite and demand our attention, witness, and responsible engagement” (p. 8).

Samantha Cromptvoets’s (2006) Breast Cancer and the Post-Surgical Body is concerned with the lived experience of women, of the mastectomized body, with specific attention to the “micropolitics of breast cancer organizations and the political economy of breast restoration” (p. 4). While Cromptvoets’s study is unlike my own in that it can be more comfortably situated within a sociological framework, it too is an interdisciplinary project drawing on the “phenomenology of illness experience, narrative construction of identity, feminism and the body, and the politics of health” (p. 4). Specifically, Cromptvoets’s attention to how the body is “negotiated, constituted, mobilized, and performed by and for women with breast cancer” (p. 4) is in tandem with my own thinking. Cromptvoets explores how “the mastectomized body and self is constituted in language, in the stories that women tell about their illness experience, and in practice, how both words and things perform the post-surgical body in particular ways” (p. 4). As she suggests, it is immanently important to examine how the post-surgical body is constructed and reconstructed in the context of breast cancer culture.
Crompvoets (2006) argues that the normative underpinning of breast cancer culture “allows no space for women to reconceptualize their bodies as normal, feminine or complete in the absence of a breast or breasts” (p. 4), because the mastectomized body “is positioned as transient, to be ‘fixed’ as soon as possible” (p. 4). Crompvoets questions the social construction of the singularly “acceptable” post-surgical body, pointing to how the restoration of health and wellbeing in breast cancer culture is inextricably linked to breasts and the successful attainment of pre-surgery appearance (p. 3). In exploring the particularities of the lived body she demands that we take into account “the particular gendered modalities, structures and conditions of our embodied being-in-the world” (p. 19). In line with my own thinking, Crompvoets is invested in exploring the ways knowledge of breast cancer is produced and performed and, like Charon (2006), Stacey and Bryson (2012), Ehlers and Krupar (2012), points to the necessity of turning to bodies as knowledge-makers, because she wants to draw attention “to what is left unsaid about the post-surgical body” (p. 16).

For example, Sarah Lochlann Jain (2007a) describes how breasts forced her “to live in a sort of social drag” (p. 514). “Rather than being a welcome harbinger of womanhood,” she says, “breasts had stolen my tomboy youth,” ushering in further normative expectations of how to properly behave as a woman (p. 514). Paradoxically, then, a breast cancer diagnosis and the subsequent treatments presented Jain with an unexpected “opportunity to have my body approximate, albeit inexactily, my body image in a way that did not come with the moral baggage of an unnecessary surgery” (p. 514). After her first mastectomy, but before her second, Jain found it difficult to navigate the implied public body politics of having only one breast (p. 512). “It seemed implicitly like a political statement to not wear a prosthesis, even when the only ‘politics’ was in having neither prosthesis nor second
mastectomy rather than any actual action” (p. 512). Furthermore, she did not want her body to be coded by others as making a “permanent radical political statement” (p. 512) yet, on a daily basis, the prosthesis was both uncomfortable and awkward (pp. 512-513). “So I did not want to have to wear a prosthesis just to seem as though I were not making a statement” (p. 513); however, just one breast “seemed to force me into permanent warrior status” (p. 513). Overwhelmingly then, a double mastectomy not only offered Jain an opportunity to feel more comfortable, it also provided her with an opportunity to embody a differently nuanced gender presentation, because for a “cancer butch” “mastectomy offers a recuperation (of sorts) of that pregendered adolescent space” (p. 526).

Jain (2007a) does not evoke a transgendered autobiographical narrative trope of being born into the wrong body, stating explicitly, “I do not want to be a guy nor do I experience myself in the wrong body” (p. 514). In fact, she claims that breasts did not make her “particularly girly” (p. 514) and not having them does not make her “more manly” (p. 514). If she was initially unsure of how to negotiate the implied body politics of electing a second mastectomy, Jain went ahead with her decision and, after the fact, wrote poignantly about her experiences and conflicting emotions in relation to breast cancer diagnosis and treatment in “Cancer Butch,” an academic article which also functions as a disruptive breast cancer narrative. Delese Wear (1993) points to how literary representations of mastectomy engage with the complexity of representing the body and emotions, and explores how authors write denial and fear, sadness and pain, shame, and, in certain instances, transcendence after breast cancer surgery. In turning to narratives that specifically engage with mastectomy as producing specific knowledges, scholarly work in gender and sexuality studies that seeks to
challenge the normative and heteronormative assumptions placed on bodies and subjectivities diagnosed and treated for breast cancer is particularly relevant.

Throughout “Cancer Butch” Jain (2007a) effectively critiques the “redoubling of femininity” that runs through “the entire biomedical complex of cancer treatments” (p. 504). Firstly, not only is a cancer diagnosis made specifically of the breast, there is a pervasive insistence on trying to attach normatively gendered femininity to those diagnosed with breast cancer. This redoubling of femininity can be found in

the pamphlets that let women know how soon after mastectomy they can return to ‘washing walls;’ the mascot color pink, understood to be ‘comforting’ to women; the Look Good, Feel Better classes that teach women how to use cosmetics to make themselves look good throughout treatments. (p. 504)

As a result, “breast cancer demands a surrender to femininity and to the mortality doled out by the feminine body” (p. 505). “The forces that distribute that mortality are multiple, and range from the way in which mammary tissues are particularly susceptible to carcinogens, to homophobia in health care, to the widespread dismissal of women’s complaints in medical care” (p. 505). Thus, Jain calls for a queer analysis of breast cancer because it has the potential to offer more than the fact that in the United States lesbians may still be the most undertreated subsection of the population (p. 506). She rightly insists that queer critique “provides a radical intervention into the ways in which gender is constituted and inhabited,” because where breast cancer is concerned “the relentless hyper- and heterosexualization of the disease results in something of a recursive process through which gender is produced and policed” (p. 506).
Through her own disruptive breast cancer narrative and critique of breast cancer culture, Jain (2007a) illustrates that the body provides a rich site of queer theoretical investigation. Still, Jain reminds us,

I draw a space in which cancer can come out of the closet in a way that is not about comforting ourselves and each other, and that is not about righteous anger but, rather, is a space of mourning and a space for the agency and material humanity of suffering and death. (p. 506)

In calling for attention to the ways knowledges, narratives, and bodies operate in relation to the biopolitics of breast cancer, Mary K. Bryson and Jackie Stacey (2013) also call for turning to necessary instances of “queer cancer” (para. 2). Here, these practices “represent a relationship to health and embodiment that is predicated, not on normalcy, but predicated on troubling norms” (para. 1) and where health knowledge might be informed by the complexity queer narration of cancer illuminates “across the seemingly incommensurable idioms of biomedical knowledge and embodied experience” (para. 29). Finally, the scholarly literature in qualitative health studies which employ a narrative approach to the study of illness and disease directly informs my own approach to breast cancer narratives, as these narratives also struggle to make sense of, and disrupt, biomedical knowledge and embodied experience.

2.5 Interdisciplinary Health Research and Narrative Inquiry

The editors of Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma argue that

Biomedical discourse tells a particular story about health and illness, based on distinct models and metaphors, that is conveyed through such texts as diagnostic manuals and
training handbooks for health practitioners. That story can be confirmed or contested by accounts from individuals or groups about their own experience of disease, disability or trauma. What is evident is that events or symptoms do not carry the same meanings when they are framed differently or viewed from different perspectives. 

(Raoul, Canam, Henderson & Paterson, 2007, p. 6)

The study of patients’ written and visual representations of illness and disease is well established in the humanities by literary scholars and historians, cultural studies, and gender studies researchers. These researchers “are interested in how artistic expression and form relate to the body that produces those representations” (Raoul, Canam, Henderson & Paterson, p. 3). As editors Valerie Raoul, Connie Canam, Angela Henderson, and Carla Paterson explain in the introduction to the collection Unfitting Stories:

“Narrative” is used as an object or means of inquiry, from political science to psychology, from social work to applied ethics, yet the ways in which we receive, produce, analyze, and deploy the term, as well as the stories involved, vary considerably from one discipline to another. This is an area which demands multidisciplinary, cross-disciplinary, transdisciplinary, or interdisciplinary collaboration to enable a sharing of perspectives that can lead to new insights. (pp. 3-4)

Of particular importance to this project, is the potential of an interdisciplinary approach to breast cancer narratives to affirm scholarship that foregrounds the study of narrative but engages with it by interdisciplinary means, with an insistence on developing new insights otherwise exhausted by a disciplinary approach.
This project is situated at the intersections of women’s and gender studies, literary studies, and qualitative health research; conceivably, a location not unlike interdisciplinary research conducted in the field of medical humanities. Pedagogical activities in the medical humanities bring the content, concepts or methods of humanities disciplines to medical education in order to explore illness, disability, pain and suffering with the intention of fostering, encouraging and motivating future health care professionals to integrate into their clinical practices not only self-reflexivity but also empathy (Shapiro et al., 2009). One would hope that they also pay attention to cultural competency in relation to the diversity of patient experiences. At best, the medical humanities might also highlight how medicine functions through discourses, practices and narratives and has the potential to produce patients through the institution of biomedicine. Illness narratives—storied accounts of illness, disease, disability, pain, suffering and trauma—are taught in a medical education context, in part, because of the powerful affective dimensions of patient experience these stories might convey; narrative is taught because it is deemed to function unlike any other type of teaching tool. That said, Delese Wear and Julie M. Aultman (2005) caution that medical students are not always willing to critically engage with difficult narratives by “unruly subjects” (p. 1056). Therefore, they stress the need for a robust critical approach to narrative inquiry, one that diverges from the study of individuated realities to the collective processes of oppression and suffering, in order to encourage students to enter a critical space that engages with the lives of others as represented in narrative form (p. 1057).

Segal (2007b) reminds that we must fully integrate narrative into health research because of what might be lost without such stories of patient experience and distress:
Narrative…gives meaning and texture and humanity to what might otherwise be just cases; the embodiments of disease, disability, and trauma. Narrative is the corrective to biomedical discourse, which is, conventionally at least, characterized by a thinness in descriptions of patient experience, a tendency to measurement and quantification, and an embrace of the mores of Foucault’s clinic, where the “individual in question was not so much a sick person as the endlessly reproducible pathological fact to be found in all patients suffering in a similar way” (Foucault 1973, 97). (p. 20)

Narrative then, as a corrective to biomedical discourse, might provide the very opposite of scant description where patient experience is concerned. Instead, at best, it might provide a window into the complex, often painful and distressing, world of patient experience. Moreover, Segal (2007b) argues that narrative provides a means of undertaking postdisciplinary health research, as the study of narrative becomes an “interesting subset of non-traditional health research” (p. 19).

In “Interdisciplinarity and Postdisciplinarity in Health Research in Canada,” Segal (2007b) uses the term “postdisciplinarity” “to indicate the loosening of disciplines suggested by multi-, cross-, trans- and interdisciplinarity, but characterized especially by the most radical of the constructs under discussion: interdisciplinarity” (p. 16). “Postdisciplinarity recognizes, and preserves, the virtues of disciplinary research,” Segal explains, “while it refuses to enshrine disciplines in the form in which they were invented” (p. 16). Segal argues that postdisciplinarity is “the next way of conceptualizing research” (p. 16). “Disciplines persevere,” she says, “but they may also be crossed, recombined, exploded, or disrupted to advantage” (p. 16). As she argues, “Narrative study profits from the specific knowledges of disciplines—but because it frequently resists classification, narrative study is also
postdisciplinary” (p. 21). “Narrative study,” she points out, “includes research on, with, about and through stories” (p. 21). In providing close readings of disruptive breast cancer narratives, this project will also contribute to a postdisciplinary approach to health research; at base, however, this project can be understood as “interdisciplinary” in approach, theme, and theoretical perspective.

In their introductory remarks, “Making Sense of Disease, Disability, and Trauma: Normative and Disruptive Stories,” the editors of Unfitting Stories suggest two types of illness narratives—“normative” and “disruptive” stories. Raoul et al. do not undertake to define what a “normative” or “disruptive” narrative is, or the differences between the two types of narrative, presumably because the authors assume that a reader would be able to easily differentiate between the two. In “Breast Cancer Narratives as Public Rhetoric,” Segal (2007a) also names two types of illness narratives in exploring examples of what she calls “conventional” and “unconventional” breast cancer narratives. Of conventional breast cancer narratives she argues that “we know the standard story is generic in part because we recognize its violations” (p. 13). In other words, we recognize a disruptive or unconventional illness narrative because, in part, we can so easily identify a normative or conventional one. Segal also terms the unconventional breast cancer narrative a “renegade” cancer story, because it abandons previously held beliefs in favour of telling a different type of cancer story. The disruptive breast cancer narratives I engage with throughout this project could also be termed “unconventional” or “renegade” and they are often promoted or even proclaim themselves as such. “Once in a while, we hear the sound of a renegade story failing” (Segal, p. 13). Without a doubt, sometimes a so-called “unconventional narrative” fails to deliver a
truly unconventional cancer story. Yet not all autobiographical breast cancer narratives fail to disrupt and perform an unconventional or renegade narrative.

While certain narratives may be best understood to disrupt normative breast cancer knowledge Raoul et al. (2007) argue that

normative or disruptive stories can be used in various ways, fulfilling functions of which the teller may be more or less aware. They can also be analyzed from a range of methodological perspectives that raise academic and ethical issues regarding what can or should be done through or with personal narratives. (p. 6)

It is not enough to simply analyze how personal narratives of illness differ from the narratives biomedical discourse tells of disease, disability, and trauma. Both normative and disruptive stories can be taken up and used in a variety of ways by the qualitative health researcher.

“Bioethicists invoke personal stories as an alternative to universal principles in their attempts to understand ethical dilemmas from the perspective of patients and their families” (Raoul et al., p. 3). The uptake illness narratives are given in scholarly discourse—the way, for example, personal stories of breast cancer can be used to support or contest the ideologies and discourses of dominant breast cancer culture—can fulfill functions the storyteller may, or may not, be aware of. This situation does not present reason enough to refrain from using personal stories in such ways. The researcher, as first a reader of illness narratives, must pay attention to the specific ethics individual illness narratives present in attempting to translate an experience of illness into narrative form for public consumption. Ethics are involved in both the writing and reading of illness narratives, as much as ethics are also involved in the researching and study of illness narratives. As feminist bioethicist Hilde Lindemann Nelson (1997) argues, we do many things with stories (p. x). As writers, readers and researchers we
construct and read stories, we invoke and counter them, analyze and compare them, and we also parody them (Nelson as cited in Raoul et al., p. 6).

While in this project I focus on post-millennial breast cancer narratives, I also read genealogically in order to explore “discontinuities, but also, paradoxically, surprising continuities, those echoes of counternarratives that reverberate across time and space” (Diedrich, 2007, p. xviii). In order to examine, especially, the performance of politics, emotion and gender in disruptive breast cancer narrative of the current historical moment, I also turn to disruptive narratives written in the 1980s and 1990s. At first glance, anger appears a more prominent feature in narratives written in that era than in breast cancer narratives currently in popular circulation. Anne Hunsaker Hawkins (2005) describes a shift in tone, and intent even, in pathographies or illness narratives written the late 1970s. She describes pathographies of the 1980s and early 1990s as demonstrating a “cultural discontent with traditional medicine” evidenced by the “expression of anger at callous or needlessly depersonalizing medical treatment and by a concern with alternative medical therapies” (p. 5). She names a subset of illness narratives “angry pathographies” which are “intended to expose and denounce atrocities in the way illness is treated in America today” (p. 6). “These books testify,” she says, “to a medical system seen as out of control, dehumanized, and sometimes brutalizing” (p. 6). “They are written from a sense of outrage over particular and concrete instances of what is perceived to be the failure of medicine to care for the ill” (p. 6).

Now, there is a shift in breast cancer narratives from anger at maltreatment in biomedicine to anger at the normative politics of breast cancer, or what Barbara Ehrenreich (2001) terms “the mainstream of breast-cancer culture” (p. 48).
In this study of disruptive breast cancer narratives, I will pay specific attention to the affective terrain these narratives traverse. I am particularly motivated to engage with feminist theorizing of anger as it is informed by cultural studies of emotion, a scholarly field that parts ways with psychological and psychoanalytic understandings of feelings and affect. What first propelled me into this research project was a general questioning of why anger is largely discordant within cultures of illness and very specifically within breast cancer culture. I wondered if feminist and queer theoretical perspectives might help to illuminate this question. As such, in my research chapters I endeavour not only to engage with the performances and performativity of emotion in disruptive breast cancer narratives, but also to invigorate debate on the possibilities and problematics of theorizing anger from feminist, queer, and trans perspectives. Obliquely, then, I aim to expand Hawkins’s description of angry pathographies and to illuminate the contemporary sociohistorical context these angry breast cancer narratives now engage with. Next, in Chapter Three, I turn to the problematics of theorizing illness narratives and the ethical considerations one must engage with when undertaking a project informed by feminist approaches to narrative bioethics.
3 Theorizing Illness Narratives: Feminist Bioethics, Narrative Ethics and Disruptive Breast Cancer Narratives

3.1 Theorizing Illness Narratives

Throughout *Treatments: Language, Politics, and the Culture of Illness* Lisa Diedrich (2007) is “concerned with the relationship of the memoir form to transformation (of selves, language, and institutions) and conformation (to established narrative and institutional structures and practices)” (p. viii). She is interested in both disruptive and normative stories of illness. Here, Diedrich considers what kind of cultural work, in a contemporary Western sociocultural context, illness narratives do “for those who write them, for those who read them, and for those institutions (literary, medical, cultural) that they become a part of or remain outside of” (p. vii). In fact, she queries,

What sort of subject is formed in the practice of writing memoir in general, and illness narratives in particular? What sorts of knowledges are articulated in such writing? How are these knowledges different from expert medical knowledges, and are they capable of transforming expert medical knowledges? How does language both capture and fail to capture the “scenes of loss” portrayed in illness narratives? And, finally, what sort of ethics emerges out of such scenes of loss and the attempts to capture them in writing? (p. vii)

In addition to these questions, Diedrich explores throughout her interdisciplinary project the work illness narratives do “personally, politically, and culturally” (p. xvii). Overall, she also endeavours to explore questions of subjectivity and embodiment, literary practices, knowledge creation, and ethics in relation to the writing and study of the memoir form. Indeed *Treatments* is about “bodies, language, and death; it is about illness, culture and
politics, and the discourses and practices of medicine, literature and philosophy” (p vii). I point to the major themes of *Treatments* in part to acknowledge the similarities between this text and my own project, but also as an opportunity to articulate the differences between our projects, especially from theoretical and methodological perspectives.

Diedrich reads illness narratives as “case studies” and draws from three theoretical frames—poststructuralism, phenomenology, and psychoanalysis—which she acknowledges could be considered “incompatible,” yet can also be “linked under the more expansive disciplinary rubric of feminist theory” (p. ix). In reading illness memoirs as case studies she also turns to genealogies of illness narratives, noting that Foucault suggests “genealogy” as a historical method which “seeks to unravel the progressive and linear history of the historicists” (p. xviii). Diedrich’s project is decidedly Foucauldian in theoretical perspective. In this chapter, and throughout my project, I turn to feminist theory, specifically feminist bioethics and especially narrative approaches to bioethics which have been positively informed by theoretical advances made in literary criticism. Narratology and the narrativist turn in the social sciences and humanities by extension, provide an interdisciplinary approach well suited to my object of study, disruptive breast cancer narratives. I place narrative disruption in a context of historical and ongoing feminist interventions into dominant discourses, including biomedicine which remains a discourse rife with examples in need of feminist bioethical inquiry. These feminist interventions speak out not only against how women continue to be marginalised by hegemonic power embedded in biomedicine, but also how gender variance is intrinsically marginalized within this system as well.

The rubric of feminist theory I am invested in advancing already attends to how gender functions as but one category of analysis, and recognizes that it is intersectional
analysis including attention to race, sexuality, dis/ability, age and socioeconomic class—in addition to gender—that proves most cogent. Moreover, it is at the intersections of gender, race, sexuality, ability, age and class that sociocultural and societal privileges and oppressions not only inform identity formation but also have great power over the material, physical, and emotional realities of subjects. As Leslie McCall (2008) argues, since critics first pointed to the limitations of gender as a singular category of analysis, feminists have embraced “the relationships among multiple dimensions and modalities of social relations and subject formations,” (p. 1771) to a degree not seen elsewhere in the academy. Through intersectional analysis the very concept of narrative identities formed in relation to illness can be situated, explicated, and seen as complicated. In this project narrative, “disruption” can be understood as a feminist “talking back” to biomedical discourse, mainstream breast cancer culture, and categorical identities such as the breast cancer “survivor.” Certainly, feminist theories have stressed that how we theorize and why is of great importance because theorizing is no less than a practice with significant sociopolitical consequences (Wolf, 1996, p. 21) and in order to bring “illness identities” and “narrative disruption” together, a theoretical framework must be explicated. I undertake to engage with politically salient bioethical perspectives, and because there is no such thing as a neutral bioethics (Wolf, 1996, p. 21) I turn to feminist narrative bioethics. It is important to remember that the project of bioethics is governed by a moral and political claim to prevent or reduce harm to vulnerable populations and subjectivities. In this chapter, I will first provide an overview of feminist bioethics and then narrative bioethics, then review the canonical literature on illness narratives and its sometimes complicated relationship to both feminism and bioethics, and
finally turn to what discussions of “counternarratives” might offer in theorizing disruptive breast cancer narratives.

3.2 Feminist Bioethics

The 2010 text *Feminist Bioethics: At the Centre, On the Margins* argues that the field of feminist bioethics is at a critical juncture, where it might be subsumed into mainstream bioethics or remain “a marginal voice overtly challenging consensus” (Fitzpatrick & Scully, p. 1). While the discipline of bioethics encompasses various fields of inquiry, including medical ethics, research ethics, clinical ethics and biomedical ethics (p. 1), feminist bioethics asserts that “dominant ways of doing bioethics are fundamentally gendered and that they contribute to culturally inscribed oppressive practices” (p. 3). Whereas “mainstream bioethics” remains poorly defined and could refer to any number of practices synonymous with particular strands of liberal or neoliberal bioethics, the term itself signals “prevailing theories and practices in bioethics that are not feminist and that are therefore felt to be oppressive of women and other marginalised groups” (p. 6). Feminist inquiry in bioethics is invested in critiquing “oppressive and exclusionary practices in mainstream bioethics and seeks to provide nonoppressive, nonexclusionary alternatives” (p. 3). Susan Wolf (1996) argues that it is not incidental that bioethics has overwhelmingly ignored questions of gender and feminism within its foundational discussions and debates. From its beginnings in the 1960s and 1970s, the field of bioethics has been overly informed by liberal individualism and an occlusion of sociocultural context; it is marked by “deduction” from extant ethical principles but not “induction” from examining concrete cases. It situates ethical dilemmas as problems between individuals or those of entire societies, yet fails to examine the
significance of distinct sociocultural formations. It lacks critical reflexivity in thinking through whom the field serves and how (Wolf, 1996, p. 5).

Bioethics, as a modernist enterprise emerging at a time of other rights-based movements of the 1960s and 1970s, has focused on protecting vulnerable patients and research subjects, the ethics that guide physicians and scientists, and the relationship between medicine, science, and social meaning (Wolf, 1996, p. 10). Bioethics could be described as the explication and study of the ethics of healthcare, medicine, and the biological sciences. As a field of study, it has undertaken to debate many issues that intimately concern women’s bodies, such as abortion, surrogacy or assisted reproduction, which leads one to wonder how feminist perspectives could have been omitted from original analysis (Wolf, 1996, p. 12). Whereas the field of bioethics has usefully exposed the power differential between doctor and patient, feminist bioethics has investigated the various power differentials embedded in biomedicine and, as Fitzpatrick and Scully (2010) argue, “feminist bioethics has made it a priority to move the analytic gaze beyond the clinic or laboratory to consider the social and political contours of moral responsibility” (p. 3).

Recent texts illustrate feminist bioethical inquiry in action, as they investigate the social, political, and medical implications of breast cancer as it manifests not only as a disease but also as a culture with far-reaching implications. Both Maren Klawiter’s *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism* (2008) and Samantha King’s *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy* (2006) move outside the clinical encounter of biomedicine to examine how ethics, cultural politics and biopolitics collide in the various disease cultures of breast cancer. Klawiter offers an alternative sociological perspective, framing breast cancer culture as a complex social
movement in the United States in the twentieth century. She explores “social movements without the sovereign”—a poststructural analysis of power lacking a definitional centre—an approach “feminists have long advocated” because it “places the relationship between power and bodies at the centre of the analysis” (p. xxix). Klawiter explores how women with breast cancer come to perform in this changing social landscape,

by exploring the ways bodies figure not only as sites of organic suffering and targets for the inscription of power but also as sources of subjectivity, anchors of identity, and flexible, expressive symbols and signifiers of competing discourses and practices of health, normality, risk, deviance, disability, and disease. (p. xxx)

Thus, Klawiter adopts a Foucauldian theoretical approach in turning attention to “regimes of practices” to describe how breast cancer is treated in individual bodies as well as publicly managed in populations (p. xxvi). She further shifts attention to the San Francisco Bay Area, situating it as a “field of contention” and speaks to three “cultures of action” which overlap and interact with each other shaping “the local contours of breast cancer” (p. xxvi). In order to tell a narrative of the development and subsequent transformation of the “regime of breast cancer” in the twentieth century, and “its implications for the emergence of new subjects, social groups, solidarities, and social movements” (p. xxvi), Klawiter focuses on “technologies of the body” which she believes central to the “social, spatial, temporal, visual, and emotional ordering” (p. xxvi) in each of two disease regimes.

First, Klawiter conceptualises the “regime of medicalization” during the early decades of the twentieth century, when cancer care moved from home to hospital and surgeons performed the authoritative treatment of Halstead radical mastectomy; accordingly, “breast cancer was discursively constructed as a curable disease” (p. xxvii). Women with symptoms
of breast cancer were designated “at risk” and if diagnosed with the disease, “a new social script” (p. xxvii), “the sick role,” was institutionalized by biomedicine, as Talcott Parsons (1951) first articulated. As Klawiter argues, “The sick role reinforced the paternalistic authority and knowledge monopoly of physicians, on the one hand, and the dutiful compliance and forced ignorance of patients, on the other” (p. xxvii). The sick role also closeted convalescence and ensured that women who had undergone mastectomy would be invisible to each other and to the public (Lorde, 1980; Klawiter, 2008, p. xxvii). Second, the “regime of biomedicalization” in the 1970s and ’80s, marked by changes in cancer education, early detection, diagnosis, treatment, and post-treatment care, gave rise to the emergence of informed patient consent, variety in surgical procedures and adjuvant treatments, patient support programs, and a redefining of the roles and responsibilities of doctors and patients (Klawiter, p. xxvii). Now “the emergence of new subjects and social relations of disease facilitated the formation of new collective identities, social networks, solidarities, and sensibilities” (Klawiter, p. xxviii). Klawiter charts an important shift in the regime of the disease from breast cancer’s medicalization to its biomedicalization and, by extension, points to a shifting context of issues which should be of bioethical concern.

In this ethnographic study, Klawiter (2008) also names and explores three “cultures of action,” illustrating how each “embodied, enacted, emoted, and enunciated a different vision of what is and what ought to be” (p. xxvii) in breast cancer activism and culture. The first, “the culture of early detection and screening activism,” symbolically represented by the pink ribbon, focuses attention on expanding breast cancer screening programs and with presenting upbeat images of breast cancer survivorship. In this culture of action “hope, gratitude, the individual heroism of survival, and faith in the progress of science and medicine” are
foregrounded (p. xxix). The second, “the culture of patient empowerment and feminist treatment activism,” focuses on providing resources and services to women with breast cancer, lending emotional support and sharing medical information. It is also concerned with giving voice to women with cancer, urging the cancer establishment to change its research priorities and practices, and forming a collective identity known as “women living with cancer” (p. xxix). Here, “anger was a common emotion—derived in part from a sense that women with cancer had been betrayed by the cancer establishment—but anger was complemented by compassion and support for women living with cancer” (Klawiter, p. xxix). Third, the “culture of cancer prevention and environmental activism” stresses toxic environments and victimized communities, and seeks to reframe cancer—and breast cancer in particular—as an environmental disease (p. xxix). It focuses on “advocating, designing, and participating in research exploring the links between cancer and the environment” (p. xxix), as well as finding ways to reduce exposure to carcinogens. In this culture of action, anger was the predominant emotion (Klawiter, p. xxix). In sum, not only is Klawiter’s study an essential resource in that it conceptualises, maps and theorizes the similarities and differences within the cultures of action that constitute the social movement arising from breast cancer, it also points to the range of power dynamics and potential bioethical concerns embedded within these same cultures.

Samantha King (2006; 2010b) also offers an alternative sociological account of breast cancer culture, with specific attention to how the agendas, strategies, and policies of corporations, governments, and large nonprofits work to produce and reinforce the social aspects of the disease. Further, King questions how the disease is culturally performed and predominantly represented, and “the distinct set of signs and symbols—style even—now
associated with it” (p. xxiii). For example, while the pink ribbon has become the ubiquitous symbol of breast cancer culture, it has also come to represent “an instantly recognizable set of meanings and values related to femininity, charity, white middle-class womanhood, and survivorship” (King, 2006, p. xxii). The pink ribbon is not only broadly symbolic, it has come to represent a particular set of practices and performances within breast cancer culture, and the very style of public performance of the disease. King’s study, like Klawiter’s, suggests that the cultural ethics and bioethical concerns brought about by breast cancer culture demand further attention, especially as pink ribbon culture dominates public discourse about the disease; breast cancer has become a “philanthropic cause par excellence” (p. x) and breast cancer awareness campaigns now have global implications (2010a).

The transformation of the disease into the individually oriented rhetoric represented by mainstream breast cancer culture peaked in the 1980s and ’90s in a context of “powerful antifeminist backlash” (King, 2006, p. x). This context, King argues, worked to stifle radical politics and encouraged “women-centred social movements to distance themselves from explicitly feminist agendas” (p. x). At the same time, the “self-help” movement, as enthusiastically embraced in the United States, set the stage for a breast cancer movement more aligned with “internal reflection and transformation than towards external or structural change” (p. xi). Indeed, breast cancer has been culturally transformed from a private disease associated with stigma and isolation, to an overlooked epidemic in need of public debate, “to an enriching and affirming experience” (King, 2006, p. x) where women with breast cancer are now rarely understood first and foremost as “patients,” but upon diagnosis already understood as “survivors.” The embodied cultural performance of breast cancer has shifted then from victim, to patient, to survivor. Now, “the figure of the breast cancer survivor
emerges as a beacon of hope who, through her courage and vitality, has elicited an outpouring of ‘American’ generosity” which, “we are led to believe, will ensure that the fight against the disease remains an unqualified success” (King, 2006, p. x). Within mainstream breast cancer culture then, the strength and optimism of the breast cancer survivor, paired with the copious research dollars raised, are unquestionably understood as the best weapons to do battle with the disease (King, 2006, p. x). As a result, King argues:

this in turn has profound implications for how breast cancer is experienced by those who have the disease, how it is approached by the biomedical community who research and treat it, and how it is understood in the culture as a whole. (p. x)

This situation also has profound implications for how autobiographical narratives of breast cancer are written and performed, framed and shaped, and experiential knowledges deemed allowable and worthy of inclusion. In sum, breast cancer narratives are rife with potential for feminist bioethical inquiry, and feminist narrative bioethics specifically emerges as a subfield of study appropriate for their analysis.

3.3 Narrative Bioethics and Feminist Inquiry

Narratives hold a place of importance in the interdisciplinary field of bioethics, as “all bioethicists work with cases” (Nelson, 1997, p. xiv) and scholars working in the subfield of narrative bioethics use narratives to consider ethics of one kind or another, as well as reflecting on the limits of working with illness narratives in such a way. In fact, narrative bioethics has stressed “the centrality of narrative in the work of health care” (Charon & Montello, 2002, p. xi). Narrative bioethics may have first arisen as doctors, nurses, patients, and ethicists took seriously the acts of reading, writing, and telling of narratives of illness and
suffering, but this undertaking has also pointed to a need to listen differently in the numerous private exchanges within the clinical encounter, as well as to engage critically with the public life of illness narrative and narrative ethics. Hilde Lindemann Nelson, a prominent feminist bioethicist working in the field of narrative bioethics, stresses that there are many things we do with stories—as tellers, readers and researchers. Literary analysis, in the form of textual criticism of stories that are explicit narratives, or of social practices that one reads as a literary text, is one such approach to narrative bioethics. Whereas some literary critics have declared that they are “doing ethics” in their scholarship, many others do not consider themselves ethicists (Nelson, 1997, p. xi); more accurately, they believe their knowledge of literature might illuminate illness, suffering, and the contours of biomedicine. As Nelson argues, when such scholars

  bring literary criticism to bear on medicine, they are uncovering moral meanings of health and illness, identifying what counts as a virtuous practice of medicine, noting how ethical responsibilities are assigned with this practice, explaining what condemns or excuses people in the context of the clinic, describing how such identities as “noncompliant patient,” “negligent practitioner,” or “compassionate medical student” come into existence, or attending to a host of other matters that bear directly on the moral values operating within medicine. (p. xii)

Literary critics are not “doing ethics” if this necessarily entails developing and defending formal ethical systems (Nelson, 1997, p. xii). However, if “doing ethics”—in the sense of contributing to the interdisciplinary project of narrative bioethics—means reflecting on the moral aspects of particular encounters within a powerful social institution where what is said and done reveals a great deal about who we are
and what matters in our lives, then they are indeed ethicists, in at least a loose sense of that word. (Nelson, p. xii)

Importantly, a narrative approach in bioethics focuses on the stories patients tell of encounters with biomedicine and understands patients as “moral agents who enact choices” (Charon & Montello, 2002, p. xi). The stories patients tell matter very much. And these narratives deserve critical attention—not only praise for their attempts to translate pain, suffering and bodily change—if we are to seriously consider the ethical work they may or may not advance.


“Overwhelmingly, writers of breast cancer autobiography construct narratives that attempt to paint a positive picture of recovery and healing,” Herndl observes, but she questions whether this positive picture is “unproblematically true” and what political consequences it may have (p. 222). Specifically, Herndl stresses that the ethics of breast cancer narratives involve the greater problematic of ethical storytelling and of how writers’ attitudes shape the translation of physical experience, of a newly gained sense of self, of community even, into an ethical one (p. 223). Rightly then, Herndl calls for a consideration of the bioethics of a breast cancer narrative that insists on positive recovery and healing not only as an essential element of the
cancer experience, but also as an essential trope a writer must include in constructing a narrative of breast cancer.

Here, Herndl (2006) takes issue with breast cancer narratives that claim women do not have to die from breast cancer because, in truth, nearly a quarter of all women diagnosed do die from the disease (p. 238). Even worse, “to present the disease as an issue of will and of one’s recovery as a matter of attitude is to indirectly claim that those who do die from the disease just had the wrong attitude” (p. 236). Certainly, it is much easier to have a “good attitude” towards cancer when you have the financial means and the necessary support systems in place to not only treat the disease but also recover from treatments (p. 238). In 2006, according to American Cancer Society statistics, of those women diagnosed with breast cancer in the United States, women of colour and poor women are the most likely to die from the disease (p. 238). Herndl is wise to question, decry even, the ethics of a breast cancer narrative that suggests that where cancer is concerned life and death are a matter of choice because the “correct attitude” can and will see one through to positive recovery.

From this perspective, stories that depict only positive accounts of healing not only have the potential to do harm from an ethical stance, but also the potential to do harm from a bioethical perspective. Herndl, like other scholars of illness narratives (Segal, 2007a), calls for the writing of a different type of breast cancer narrative—one that dares to disrupt the terms of the standard story. She suggests that there is a necessary ethical imperative behind disrupting standardised storytelling:

Collections of different autobiographies that allow for open-ended and fragmentary confusion may be less reassuring than individuals’ narratives that end on a happy note of recovery, but they also seem more honest about the contingent state of healing
from cancer and may therefore provide better models for readers than narratives that end on a completely positive note. (p. 234)

While open-ended, fragmentary breast cancer narratives might be less reassuring, yet provide better models for the contingency of healing, there is a relative dearth of narratives that approach the telling of a breast cancer experience in such a way. That there are so few narratives that refuse to end on a happy note and instead engage with a less than positive account of recovery, not to mention diagnosis and treatment, is a complex problematic. I undertake to explore this issue throughout this project, but not to present a solution.

Likewise, Herndl stresses:

I do not think I can solve the problem of the ethics of telling a breast cancer story here, but I am interested in how these ethics play out in terms of identity and in terms of the community-building challenge to individualism that I see at work in these autobiographies. (p. 236)

Interestingly, she proposes that “we think of autobiographies of breast cancer in relation to vulnerable readers” (p. 242) and suggests that the manner of criticism she engages in “is meant to help protect the vulnerable from harm” (p. 242).

Herndl (2006) calls for a robust narrative ethics to invigorate both the writing of breast cancer narratives and the study of these same narratives. Nevertheless, she is a generous and empathetic reader of existing breast cancer narratives, naming herself, firstly, as a feminist critic who has studied illness narratives by women and, secondly, a breast cancer survivor (p. 222). What Herndl calls for is a greater diversity of stories about the breast cancer experience, as well as a more ethical metanarrative when these are read from a feminist bioethical lens. Still, she reveals:
I am also finding the role of critic (in the sense of faultfinder, not of educated reader) hard. To the extent that I distrust the autobiographer who says “be like me,” I distrust myself as the critic who would find the right way to talk about breast cancer, activism, and the ethics of illness narrative. (p. 235)

Instead of proclaiming to know the “correct way” to read breast cancer narratives, Herndl respectfully critiques this subset of illness narratives. Clearly, she intends to place breast cancer narratives and the ethics of illness narratives in conversation, but she does not intend her argument to function as “the last word” on the subject; there is a feminist ethical orientation to taking such a position. Truly, Herndl hopes to be but one voice in a larger conversation on the narrative bioethics of breast cancer narratives, a dialogue between the many who wish to advance this discourse. In undertaking to do feminist narrative bioethics, this project, like hers, can be usefully envisioned as an interdisciplinary one that takes the notion of experiencing and writing about illness and moves it into an ethical orientation in the public sphere. The enterprise of “doing narrative bioethics” should necessarily be fraught, because even though a canon of scholarship has grown up around illness narratives, this scholarship is most often “descriptive and classificatory” and infrequently critical in nature (Segal, 2005, p. 60).

While Segal (2005) writes from the perspective of a scholar studying the rhetoric of medicine and calls for researchers to study illness narratives with a more critical lens, she also asks for more diversity of participation in the project of narrative bioethics. She stresses that there is both an “epideictic rhetoric of pathography itself and an epideictic rhetoric of pathography study” (p. 61). In order to illuminate this approach to narrative ethics, she approaches illness narrative or pathography with Aristotle’s articulation of “epideictic
rhetoric” in mind; that is, the rhetoric of praise or blame. “Epideictic rhetoric is a culture’s most telling rhetoric,” she says, “because, in general, we praise people for embodying what we value, and we blame them for embodying what we deplore” (p. 61). Segal proposes three questions to consider in both the study and writing of illness narratives: “What are we doing when we compose and when we study personal narratives of illness? What is it that the work itself honors? What values does the work itself praise?” (p. 62). Segal argues that while it is commonsensical that individual personal narratives of illness perform an epideictic function within a community (p. 62), what is of concern is when “its repeated gestures enunciate values preferring certain sorts of accounts over others but also, for the same reasons, preferring certain sorts of experience” (p. 69). She says:

A reasonable concern about a generic groove for illness narratives, then, is that the genres of pathography invite us not only to report experience in certain sorts of ways….but also to interpret experience and even to experience experience in certain sorts of ways. (p. 69)

Of even greater concern, then, is that pathography has the potential to reproduce biomedical understandings illness that it originally aimed to disrupt (p. 71-72).

Segal (2005) asserts that certain types of narrative scholarship “can be read as colluding with some narratives to suggest there are better and worse ways to be ill, better and worse stories to tell” (p. 71). In fact, illness narratives and scholarship on illness narratives each constitute a discourse of values (p. 73). When this is openly acknowledged, both entities have the potential to be treated critically and “the qualities they praise and blame can be subjected to scrutiny” (p. 73). Indeed, this is a necessary intervention from both a bioethical orientation and from a feminist perspective. Kathlyn Conway (2007), who has written both
illness narrative and criticism of illness narrative, argues that critique provides a necessary scholarly intervention, because contemporary “illness narratives” have become synonymous with “triumph narratives.” In her work she aims to dispel popular beliefs about illness, beliefs made manifest in “narratives of triumph” which are problematically “predictable in plot and moral” (p. 1).

Conway (2007) admits that as she attempted to write her own self-consciously disruptive narrative of breast cancer, she felt the inexorable pull of the triumph narrative. Rather than submit to a storyline that colludes with ideas of illness as being positively transformational, Conway disputes the view that breast cancer—and suffering through diagnosis and treatment—have the potential to make anyone become a better person. While she does not wish to “impose a particular narrative on all illness or disability experiences,” she maintains that, “many who are ill or disabled do find the experience devastating even as they are asked to view it as an occasion for triumph” (p. 14). Conway acknowledges that the act of writing an illness narrative has the potential to empower patients, if only in placing them at the centre of their own stories and as agents rather than passive victims of experience. Many patients write against notions of triumph, and instead explore the “lost totality” and “catastrophe” they experience during illness, disrupting the common notion that patients write “as an attempt to impose order on experiences that are chaotic” (p. 133). “It becomes apparent,” she argues, “in reading these memoirs that certain writers are equally interested in representing in words the irreconcilable, fragmented, interrupted, or even chaotic nature of their experience” (p. 133).

Conway (2007) calls for an examination of the compulsion—evidenced by the sheer proliferation of triumphal illness narratives—to tell stories of triumph, redemption, and
closure. “By adhering to the culturally preferred narrative of triumph,” she says, “authors typically downplay or deny other dimensions of their own experience, particularly the more painful and unmanageable ones” (p. 2). Her own interest in the narrative bioethics of illness began when she was receiving chemotherapy for breast cancer and was decidedly uninspired by the many triumphal stories offered to her. She found that in these narratives, after the initial shock of diagnosis, the author always “finds a comfortable way to cope, and eventually is restored to health or achieves some kind of emotional resolution” (p. 1). Where breast cancer is concerned, the impact of normative gender constructions on women in relation to illness and narrative must also be explored, for there is something distinctly disturbing about a discourse that expects women to triumph—or purport to triumph—when diagnosed with cancer. Sayantani DasGupta and Marsha Hurst’s (2007) critical scholarship on illness narratives advances a dialogue that makes explicit the connections between narrative, gender, and illness. This intersection is “nuanced and complex” and impacted in no uncertain terms by the “gendered constructions of medicine, health, voice and vulnerability” (p. 1). Certainly, narrative and illness are both impacted by how gender is socially constructed in dominant discourses, and the notion of two distinct, fixed, stable genders is a social construct that continues to impact experiences, bodies and lives in meaningful and tangible ways (Bryson & Stacey, 2013; Stacey & Bryson, 2012; Jain, 2007a, 2007b).

Yet narratives by women, not unlike stories coming out of other marginalized communities, have the potential to reveal “alternate truths that expand traditional medical narratives since the way that women experience illness and medical treatment is very much dependent on broader social constructions of gender in society” (DasGupta & Hurst, 2007, p. 2). Illness narratives can be especially important for women because historically it is
women’s bodies and experiences that have been defined and explicdated through the dominant narratives of a patriarchal biomedical system (p. 4). “The medicalization of women’s health has sought to narrowly define experiences such as puberty, childbirth, or menopause, attributing them to biological ‘truths’ and ignoring the impact of culture, ethnicity, nationality, class and sexuality” (p. 4). Furthermore, a master narrative in biomedicine assumes that medicine and the work of doctors is heroically masculine, while patients are correspondingly constructed as passive, weak, and feminine (p. 2). This dichotomy, reminiscent of Cartesian dualism, reproduces the idea that women are not only overwhelmingly defined by the body rather than the intellect, but are further aligned with a repudiated body with its inherently “feminine” “frailties, illnesses, and disabilities” (p. 3).

In talking back to this discourse, DasGupta and Hurst (2007) assert that a genealogy of women’s illness narrative has spoken to more than the individual, subjective experience of illness. Instead, these narratives engage in “multiple narrative modes of history telling” such as “the personal, communal, and institutional” (p. 12). “Women’s narratives,” they argue, “not only reveal realities about familial and social groups but larger socio-political forces” (p. 2). Thus, women’s illness narratives have the potential to be not only individually emancipatory but also collectively empowering in the public sphere: “Women’s narrative stories challenge professionals to confront the social structures as well as the personal experiences of caring by translating the illness experience into political action” (p. 14). Illness narratives by women also can inspire collective activism by making explicit the contingent identities that are formed in relation to community and cultural affinity (p. 14). As DasGupta and Hurst understand it, throughout the genealogy of women’s illness narratives there has also been an urge to connect “the experience of one woman to public womanhood”
in a way that advocates changing “the experience of many through the voice of one” (p. 12).

In sum, DasGupta and Hurst’s scholarship exemplifies a feminist approach to bioethics where narratives are read through an intersectional feminist lens and seek to both name and reveal the complexity of the ethics of writing and critiquing illness narratives.

If feminist bioethics remains on the margins of bioethics, feminist narrative bioethics also remains on the margins of illness narrative scholarship, although exemplary examples of this approach have been written since the formation of the field of study. For example, in “Autopathography: Women, Illness, and Lifewriting” (1991/1999), G. Thomas Couser contends that traditional literary autobiography ignores physical concerns and the body in favour of a masculinist privileging of the intellect over the corporeal. Couser argues in no uncertain terms that it is because of a continued association of “masculinity” with the intellectual and “femininity” with the corporeal that illness was omitted from canonical literary autobiography. These silences in traditional autobiography, then, provide room to consider what place illness should hold in an autobiographical account of one’s life. Moreover, Couser applauds “autopathography,” or autobiographical accounts of disease, illness, and disability. He argues that “autopathography offers an honest acknowledgement and assessment of the human condition as both flesh and spirit” (p. 163). He does not find it coincidental that many more recent works of autopathography were written by women. Autopathography, he argues, “corrects centuries of Western over-emphasis on the mind at the expense of the body” (p. 163).

In connecting the omission of illness from literary autobiography to an overvaluing of masculinity and the intellect at the expense of femininity and the body, Couser (1991/1999) inadvertently makes the case that women are particularly well-suited to writing
autopathography. Nevertheless, Couser is not arguing that women are embodied in particular ways so as to be innately aligned with the pathological. For he understands the development of autopathography as a sign of “cultural health,” rather than “cultural pathology,” as it is “an exploration of our condition as embodied selves” (p. 164). When he calls for a consideration of embodiment and autobiography, he believes this to be a culturally salient point of connection. Indeed, Couser makes explicit that while women and ill people are both marginalized, but in different ways, women who are ill are doubly marginalized: “With recent developments in autopathography, then, we have a return of the doubly, or perhaps triply, repressed—an overt, unembarrassed, unapologetic representation of the ill, female body” (p. 172). The act of writing autopathography, then, provides some manner of antidote—a talking back and a disruptive feminist intervention—to the various processes of both medicalization and marginalization. Couser argues:

If illness is a literary no-man’s land, it may be, by default, a terrain available for women to map, a zone in which to rehabilitate the body as a literary subject, and a site on which to challenge the conventional domination of mind over body. (p. 172)

In making connections between women, autopathography, and the potential for a literary mapping of the overtly ill and female body, Couser also signals the ways in which writing illness narratives can constitute acts of self-assertion as well as the fact that the autobiographical self should be understood to be contingent and performative as well as embodied.

In her scholarly work on life narratives, Sidonie Smith (1998) consistently connects autobiography to performativity, illustrating how the autobiographical subject is inherently performative and how this is made manifest through the act of telling one’s story.
Performativity, as it comes to bear on illness narratives, provides a necessary theoretical intervention in the study of pathography or autopathography. The idea of “storytelling as self-expressive of an autonomous individualism” (p. 114), while driving various strands of autobiographical theory, problematically “assumes that self-identity emerges from a psychic interiority, located somewhere ‘inside’ the narrating subject” (p. 108). Instead, Smith suggests that autobiographical acts “signal the making and unmaking of identities” (p. 114).

Importantly, stories of self are not created in isolation, but are constructed in relation to others, and conceptualizing the self as an identity is always at least partially constituted and understood in relation to others. What is understood as the autobiographical “self,” Smith argues, “is not a noun, a thing-in-itself, waiting to be materialized through the text,” because “there is no essential, original, coherent autobiographical self before the moment of self-narrating” (p. 108). Instead, no matter how large the occasion or limited the audience, the “autobiographical speaker becomes a performative subject” (p. 108).

Smith (1998) argues that Judith Butler’s (1990) conception of “gender performativity” can be reconceived in terms of “autobiographical performativity” because “expressions of interiority are effects produced through the action of public discourses” (p. 109). These discourses, Smith argues, include the “culturally pervasive discourses of identity and truth-telling that inform historically specific modes, contexts, and receptions of autobiographical narrating” (p. 109). Because autobiographical performativity is inextricable from the effects produced through public discourses, including those of gender, embodiment, and illness, these discourses are important to consider when reading and writing autobiography, generally, and of vital importance in feminist narrative bioethics specifically. For, Smith argues, the “cultural injunction to be a deep, unified, coherent, autonomous ‘self’
produces necessary failure,” as the “the autobiographical subject is amnesiac, incoherent, heterogeneous, interactive” (Smith, p. 110). This failure not only makes manifest how autobiographical telling is essentially performative, but also suggests the various levels of performance at work in the autobiographical telling of illness experience.

Autobiographies—including illness narratives, pathographies, autopathographies—always have an implied or explicit reader or audience. “An audience implies a community of people for whom certain discourses of identity and truth make sense” and who have learned “to expect a certain kind of performativity that conforms relatively comfortably to criteria of intelligibility,” Smith (1998) argues (p. 110). Audiences are rarely totally homogenous. However, in certain contexts a particular rehearsal of identity includes certain elements of self and story at the exclusion of others, “the incorporations of certain narrative itineraries and intentionalities, and the silencing of others,” employing particular autobiographical voices while muting others (p. 110). That certain elements of self and story are obfuscated in the telling of an “intelligible” narrative of breast cancer has ethical implications for this subgenre of illness narrative; it also points to larger bioethical questions about how and why we should read and study illness narratives differently and more critically. Reviewing what could be considered canonical scholarship on illness narratives points to why feminist narrative bioethics is such an important and innovative project, because questions of gender and sexuality—not to mention feminist intersectional analysis—were often absent in this early scholarship which first sought to validate illness narratives as a worthy site of inquiry.
3.4 Canonical Scholarship on Illness Narratives

In 1988, in *The Illness Narratives: Suffering, Healing, and the Human Condition*, Arthur Kleinman posits not only that it is possible to talk with distressed patients about their pain and ailments, but that doctors can help in organizing this experience into narrative form. This, he argues, can be of therapeutic value to the patient. It is from Kleinman’s text that the term “illness narrative” appears to have originated. At present, I understand “illness narrative,” like Lisa Diedrich (2007), to be an umbrella term under which similar and dissimilar narratives might reside. Unlike Kleinman’s conception of illness narratives as organized, if not written, by the doctor or clinician, I adopt a more contemporary understanding of “illness narrative” as an autobiographical story of patient experience. In *The Illness Narratives*, Kleinman conducts interviews with patients and forms case studies in order to explore the multiple meanings associated with illness. He argues that “illness narratives edify us about how life problems are created, controlled, made meaningful” (p. xiii). Here, “illness takes on meaning as suffering because of the way this relationship between body and self is mediated by cultural symbols of a religious, moral, or spiritual kind” (p. 27). Moreover, Kleinman asserts that illness narratives also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition. (p. xiii)

Illness narratives, then, while culturally and socially mediated, are also uniquely personal as they are experienced and then told by patients in distress, recovering from, or living with
illness. Basically, Kleinman argues that illness narratives are essential for patient recovery as these stories provide meaning-making, understanding, and narrative coherence in the otherwise chaotic world of illness.

Following in a similar framework, Arthur Frank’s (1995) *The Wounded Storyteller: Body, Illness, and Ethics* describes those who are ill and narrate their stories as “wounded storytellers” (p. xi). In part, the ethical impetus behind his work entails shifting negative cultural conceptions of people who are ill as passive recipients of care towards one that highlights their participation and activity in society. He stresses that those who turn illness into narrative participate in transforming fate into experience; thus, “the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability” (p. xi). Frank believes that people who are ill need to tell their stories “in order to construct new maps and new perceptions of their relationships to the world” (p. 3). These stories are embodied in a particular way so that illness narratives are not simply about the body but are told *through* the body.

Frank (1995) also gestures to the sociohistorical context in which stories are told and, as he understands it, the shift from a modernist to a postmodern experience of illness (p. 3). In contrast to modernist understandings of illness, postmodern times posit illness as an “experience” and therefore “a reflection on body, self, and the destination that life’s map leads to” (p. 7). The themes of experience, body, voice, and illness all culminate in an ethics made uniquely possible in a postmodern time (p. 18). Frank argues that “postmodernity is not often described in ethical terms, and when it is, the assessment is usually that ‘postmodern ethics’ is an oxymoron,” (p. 18) yet he understands the postmodern moment to be imbued with responsibility: “The idea of telling one’s story as a responsibility to the commonsense
world reflects what I understand as the core morality of the postmodern” (p. 17). According to Frank then—and beyond the therapeutic value Kleinman perceives in telling illness narratives—patients have a “moral responsibility” to tell their narratives of illness. That said, Frank organizes illness narratives into three main categories: restitution narratives, where the narrative concludes with the return of good health; chaos narratives, where life events are connected only by contingency and lack of control; and quest narratives, where illness functions as a manner of spiritual journey. As such, Frank’s text can be read as a work of classification. In many respects, the classification system Frank provides is not only appealing but thoughtful and might be useful in a project unlike my own. Nevertheless, I question how Frank’s classification system—and moreover any text which aims to address “narrative ethics”—can be upheld when it also provides value judgements of the various types of narrative it seeks to classify.

Through Frank’s (1995) categorization of narrative types it becomes clear he also evaluates them and that the “quest narrative” is deemed the best narrative type (Segal, 2005, p. 64). For example, Frank writes: “Quest stories meet suffering head on; they accept illness and seek to use it” (p. 115). Frank also makes distinct moral assessments of illness narratives in the process of classifying them; the chaos narrative, for example, fails to even hold together as narrative (Segal, 2005, p. 64). Instead, in valorizing the quest narrative, Frank argues that it “recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice” (p. 134). In other words, quest stories fulfill a presupposed obligation to morality that other types of illness narratives errantly refuse. Throughout The Wounded Storyteller there is a tension between categorizing illness narratives—in order to provide a method to better understand
them—and engaging in critical appraisal of different types of illness narratives—which can then be seen to judge the worth, value, or even ethics of these narratives. Illness here seems universally imagined, which implies that all of us have the same access and ability to become “wounded storytellers,” with legitimate voice and audience, pursuing what could be understood as morally heroic “quest stories.” However, the various ways we are socially constructed and understood greatly shape both illness experience and narrative formation—and gender, to name but one site of difference, is intimately bound to both of these ventures.

Anne Hunsaker Hawkins (1999), in her notable text *Reconstructing Illness: Studies in Pathography*, did not initially recognize how gender—not to mention race, sexuality, age or socioeconomic class—affect the writing, or one might add, the reception, of illness narratives. Now, she is forthright in signalling what she describes as her naïveté in the text’s first edition about the various ways gender impacts and shapes illness experience and the pathographies written out of those experiences. In this text, Hawkins was the first to term autobiographical and biographical accounts of illness experience “pathography.” Pathographies, she argues,

are important as human documents not only because they record a traumatic crisis that may occur to all of us but because they represent—in their very writing as well as their content—the ways these crises may be overcome, survived, and understood. (p. xix)

*Reconstructing Illness* aims to study of the “myths, attitudes, and assumptions” that inform the various ways illness is socioculturally understood, and represented, in narrative form (Hawkins, 1999, p. ix).
To do this, Hawkins develops a “mythic thesis” which asserts that at a deep level “mythic thinking” is a powerful tool used by patients in order to cope with serious illness (p. xiii). By extension, Hawkins asserts that “authors still turn to metaphors of battle, journey, and death and rebirth” (p. xiii) in telling autobiographical stories of illness. For this reason, pathography is “our modern adventure story” (p. 1):

Life becomes filled with risk and danger as the ill person is transported out of the familiar everyday world into the realm of the body that no longer functions and an institution as bizarre as only a hospital can be; life in all its myriad dimensions is reduced to a series of battles against death; and there is the inescapable sense, both for the sick person and his or her family, of being suddenly plunged into “essential” experience—the deeper realities of life. (p. 2)

Pathographies can, then, be attempts to make sense of and to orient one’s self in the “world of sickness” (p. 2), while at the same time they offer “cautionary parables of what it would be like if our ordinary life-in-the world suddenly collapsed” (p. 2). Hawkins is also aware of the ways in which pathography can function as a model for how to be ill and the problems of such a didactic tenet in these illness narratives. In spite of that, she argues that “in its capacity to serve as a model for others, pathography plays an important role in the way it both reflects and helps shape our current mythology about illness” (p. 11).

Hawkins (1999), in agreement with Kleinman and Frank’s work of the same era, argues that pathography “returns the voice of the patient to the world of medicine,” (p. 12) a biomedical world that too often ignores patient experience in favour of medical explanations of illness and disease. Pathography highlights instead “the phenomenological, the subjective, and the experiential side of illness,” and this experiential side “can be shocking, enlightening,
or surprising” (p. 12). Notably, Hawkins adds a necessary intervention in canonical scholarship when she argues that even if pathography restores the subjective voice of the patient to an otherwise impersonal world of biomedicine, this does not mean pathographies report “the truth” or that such narratives are “true” or “real” (p. 14): “Pathographies may indeed be read as ‘true stories’ but the emphasis must be as much on ‘stories’ as the word ‘true’” (p. 14). Therefore, pathographies should not be primarily understood as accurate records of experience, but “as the ambivalence and prosaic quality of everyday living…resolved into sharp contrasts and clear-cut issues” (p. 14). To emphasise the storied elements of illness narratives is not to diminish their “truth-value” (p. 14); rather, it is to remind us that “remembering and writing are selective processes” (p. 14) and “writing about an experience—any experience—inevitably changes it” (p. 15). The difference between experience and the retrospective written account is well established in critical autobiography studies, but here Hawkins brings this theoretical perspective into dialogue with scholarship specifically on illness narratives.

Hawkins (1999) identifies three central themes in contemporary autobiographical theory and how pathography study might be critically informed by these theoretical tenets. First, pathography can be related to the ongoing questioning of the ontology of self in autobiography, and in theorizing illness narratives neither the self as “fictive” nor the self as “ineffable mystery” are wholly adequate (p. 17). Hawkins argues that in “narratives describing illness and death, the reader is repeatedly confronted with the pragmatic reality and experiential unity of the autobiographical self” (p. 17). Pathography, then, challenges the “scepticism of critics and theorists about the self” making that scepticism seem artificial or contrived (p. 17). Second, pathography addresses the cultural and social dimensions that
impact narrative form and validates the importance of sociocultural context in the writing of self. Clearly, as Diedrich (2007) and Charon (2006) also stress, the writing of pathographies involves relation to others, and cultural ideologies of illness, not to mention attitudes towards specific illnesses and practices within illness cultures. However, Hawkins stresses that “pathographies support this emphasis on society and culture, though they do so in a way that does not diminish or efface the self” (p. 17). Third, pathographies advance, in significant ways, the assertion in autobiographical theory that the past is reflected upon, reordered, or even created through the act of writing—that autobiography is the re-creation of the past (p. 18). For Hawkins, it is through re-creating the past that pathography discloses how authors change their illness experience through the act of writing. Keeping in line with her “mythic thesis,” this transformation uses mythic thinking and writing which “exposes certain metaphoric and mythic constructs about illness” (p. 18).

Within what could be understood as canonical scholarship on illness narratives other scholars have also sought to forge connections between critical studies in autobiography and the study of illness narratives. Couser (1997) highlights how illness narratives relate to other forms of life writing as well as the discourses of both illness and disability. He argues that “illness narratives reflect mixed motives: an urge for self-exploration and a desire to serve those with the same condition” (p. 15). These competing desires, one might presume, can create a kind of internal tension within the narrative as, arguably, neither aspiration can ever be completely fulfilled. In *Recovering Bodies: Illness, Disability, and Life Writing*, Couser (1997) also demonstrates how autopathography functions in the public sphere, as it is counterdiscursive to biomedical knowledge as well as to the cultural stigmatization and marginalization that often accompany illness and disability. He argues that bodily
dysfunction can lead to the writing of autopathography “by heightening one’s awareness of one’s morality, threatening one’s sense of identity, and disrupting the apparent plot of one’s life” (p. 5). “Bodily dysfunction,” he claims, “tends to heighten consciousness of self and of contingency” (p. 5). Throughout the 1990s the study of “marginalization” in the form of gender, race, class and sexual orientation moved from the margin to the centre in literary and cultural studies, but by the late 1990s few scholars had yet embarked on critical scholarly study of what Couser names the most widespread form of marginalization—illness and disability (p. 13).

Couser (1997) is concerned with the reception illness narratives receive, noting that although illness narratives are no longer ignored in popular or academic circles they remain “vulnerable to dismissal from different sides” (p. 288). Whereas some may understand illness narratives to be too sentimental to be counterdiscursive or disruptive, others may understand these stories as too focused on the body, too quotidian and mundane to be understood as literary art, while still others may argue that investment in individual fates inherently limits the emancipatory potential of these narratives. Nonetheless, Couser is particularly enthusiastic about writing “that takes advantage of bodily dysfunction to explore embodiment as a medium of experience” (p. 294), because in these texts “the details of particular illnesses or disabilities recede in importance” as “the significance of embodiment more generally comes to the fore” (p. 294). Illness narratives, in recording and validating the experiential dimensions of disease and disability, provide examples of living through and with bodily dysfunction (p. 293). “At base,” Couser says, narratives of illness are efforts to give meaning to, or find meaning in, bodily dysfunction and thereby to relieve suffering. People who narrate their illness or
disability may be said to share their bodies with others in a kind of secular healing ritual. (p. 293)

While illness narratives may function as a manner of secular healing ritual, in the current historical moment these autobiographical acts and performances of illness are too often normative and predictable. Therefore, even as I agree that illness narratives have the potential to give meaning to bodily dysfunction, I am sceptical of any notion that confessional narratives inherently work to alleviate suffering. Likewise, it is questionable if standardised storytelling might actually offer a viable way to relieve pain, because, it might instead inadvertently contribute to the pain and suffering of others, as Herndl and Conway suggest. If we turn to those disruptive instances embedded within illness narratives—or better yet turn to complete disruptive illness narratives—perhaps this is where healing, in the broadest sense of the word, might actually have an opportunity to occur for both writer and reader, teller and listener, performer and audience as we grapple with the difficult stories of illness not always publicly told and shared.

3.5 Counternarratives

In centring my own discussion of illness narratives around disruptive breast cancer narratives—in suggesting that these stories not only exist but that they are shaping discourses of disease and culture—I am also suggesting that they are doing a kind of ethical work in the world of breast cancer culture. Before I move to reading specific disruptive breast cancer narratives in the descriptive chapters to follow, I wish to first consider what Lindemann Nelson (2001) explicates as the power and potential of “counterstories.” She understands these counternarratives as produced through the dynamics of oppression, as they pull apart
the master narratives that serve as vehicles of this oppression. Counterstories, then, are useful tools serving to repair damaged subjectivities as they displace the truth-value of master narratives through telling an alternate story of experience. Hopefully, counternarratives also offer a more ethical, a more credible orientation in the world of illness. Counterstories come into being through an engagement with master narratives—troubling, disrupting, resisting, they do not exist in a social vacuum. Where counterstories are concerned, Nelson stresses that “many of them start small, like a seed in the crack of a sidewalk, but they are capable of displacing surprising chunks of concrete as they grow” (p. 169). Disruptive breast cancer narratives, as I will undertake to explicate in the forthcoming chapters, may be poised to do just this kind of work within breast cancer culture.

In selecting narratives for study in this project—those that form the focus of my research chapters and can be understood as “archives of feeling”—I chose from a diverse range of published texts, documentary films, and television sources which explicitly engage with representing breast cancer, and the cultural politics of breast cancer, from an autobiographical perspective. Indeed, these breast cancer narratives, written from the first person perspective and demonstrating experiential knowledge of the disease, were often already described in popular literature as “unconventional” or “unusual”; sometimes they were also promoted and/or self-described in such terms. In undertaking close readings of these texts, I found that sometimes what was previously understood as a disruptive breast cancer narrative failed to deliver a truly unconventional cancer story. Because I was seeking out narratives that were “talking back” to dominant discourse and resisting standardized stories of the breast cancer experience, unlike the American Cancer Society’s “Tell Your Story” campaign I was not seeking out “inspirational stories” of hope, comfort, and courage.
Conversely, I was looking for a different kind of cancer narrative, and in many ways “The Angry Breast Cancer Survivors” lead me quite seamlessly to Emily Abel and Saskia Subramanian’s (2008) *After the Cure: The Untold Stories of Breast Cancer Survivors*. Then, more specifically, I found Audre Lorde’s (1980) *The Cancer Journals*, Barbara Ehrenreich’s (2001) “Welcome to Cancerland,” and Kathlyn Conway’s (1997) *Ordinary Life*. Subsequently I turned to documentary films about breast cancer and Wendy Mesley’s (2006) *Chasing the Cancer Answer*, as well as Kris Karr’s (2007) *Crazy Sexy Cancer*, and finally, Eve Kosofsky Sedgwick’s (1993) “White Glasses,” Catherine Lord’s (2004) *The Summer of Her Baldness* and the television drama *The L Word* (2006). What I was looking for in the process of selecting these breast cancer narratives, beyond any declarative statements within them about the positively disruptive nature of these texts, were distinctive features, themes, and tropes that might facilitate a reading of the text in distinctly disruptive terms. In so doing, I found that by varying strategies and with differing degrees of success, these narratives sought to reframe the personal and cultural politics of breast cancer. They contained personal performances and autobiographical tropes of breast cancer which disrupted the dominant culture of emotion, specifically by deploying anger as a key strategy. These narratives also engaged with the politics of collective and individual cancer prevention and resisted normative conceptions of gender, sexuality and embodiment in order to queer performances of illness within breast cancer culture. Because I seek to read disruptive breast cancer narratives in relation to mainstream or dominant instances of breast cancer culture, I theoretically situate breast cancer as a cultural formation and examine the dominant cultural performance of survivorship. Certainly, the selected disruptive breast cancer narratives are counternarratives and can be understood to provide a manner of narrative repair, as they
displace and question the absolute truth-value of standardized cancer stories. These stories seek, in various ways, to etch out a more ethical—as well as less exclusive and gender normative—orientation in the world of illness as manifest in mainstream breast cancer culture.
4 Feeling Angry in Cancerland: Rewriting Breast Cancer’s Cultural Script

4.1 Welcome to Cancerland

“No, this is not my sisterhood” (p. 53) Barbara Ehrenreich (2001) writes in the final paragraph of “Welcome to Cancerland,” her blistering critique of breast cancer culture. “For me at least,” Ehrenreich writes, “breast cancer will never be a source of identity or pride” (p. 53). Instead, “what it is, along with cancer generally, or any slow and painful way of dying, is an abomination, and, to the extent that it’s man made, also a crime” (p. 53). Ehrenreich explains:

This is the one great truth that I bring out of the breast-cancer experience, which did not, I can now report, make me prettier or stronger, more feminine or spiritual—only more deeply angry. What sustained me through the “treatments” is a purifying rage, a resolve, framed in the sleepless nights of chemotherapy, to see the last polluter, along with, say, the last smug health insurance operative, strangled with the last pink ribbon. (p. 53)

Here, Ehrenreich’s anger at environmental polluters, health insurance bureaucracy, and controversially, the normative cultural politics of breast cancer culture with its emblematic pink ribbon, is as palpable as her description of cancer as an abomination and a man-made crime. Ehrenreich not only rejects a mainstreaming insistence on figuring the cancer experience as affirmative and possessing positive transformational power, but also flatly refutes that cancer can make women into prettier, stronger, more feminine and spiritual beings should they survive. Ultimately, Ehrenreich argues, “aside from the dilute sisterhood of the…support groups, there is nothing very feminist—in an ideological or activist sense—about the mainstream of breast-cancer culture today” (p. 47). Beginning with Ehrenreich’s
(2001) personal essay “Welcome to Cancerland.” I would like to explore what breast cancer culture has lost in disallowing anger, and specifically feminist anger, from its cultural mainstream. Next, I will turn to Audre Lorde’s (1980) autobiographical narrative *The Cancer Journals*, to consider how necessary feminist anger is in the wake of public cultural discourse which espouses only positive emotions as legitimate responses, personally or politically, to breast cancer. Then I will turn to Kathlyn Conway’s (1997) *Ordinary Life: A Memoir of Illness*, which aspires to the unfettered anger Ehrenreich and Lorde exhibit, but instead tells of conflicted emotions. In examining these three autobiographical breast cancer narratives spanning over two decades, from 1980 to 2001, I configure a genealogy by tracing the evolution of women’s anger in breast cancer narratives. In revisiting the literature on feminism and anger, I am also suggesting that anger should be properly situated as a necessary performance within feminist theory and organizing. Finally, I move into more contemporary terrain, shifting from notions of a feminist politic to a lesbian and queerly oriented one. Here, I touch upon *The L Word* (2006), a television drama produced by Ilene Chaiken and centred on Los Angeles lesbians, in order to offer another representation of anger performed by a woman living with a breast cancer diagnosis and the subsequent treatments.

### 4.2 Feeling Angry

Ehrenreich (2001), an activist in the Women’s Health Movement in the 1970s and 80s, rightly describes how this social movement encouraged women to share their stories, network directly, question doctors and, as a result, functioned to legitimize self-help and mutual support (Boscoe, 2004; Potts, 2000). “It is hard to now recall how revolutionary these
activities once seemed,” Ehrenreich says (p. 46), when she finds little of the original activist sentiment in the breast cancer support groups she participates in post-mastectomy. She reminds us that it was because of the Women’s Health Movement that feminist activists protested the then seemingly routine medical practice of proceeding from biopsy to mastectomy, directly, without waking the breast cancer patient from anaesthesia, never mind asking for the woman’s consent to remove her breast (Klawiter, 2008; Knopf-Newman, 2004). These activists also protested the use of the Halsted radical mastectomy, which removed chest muscle and lymph nodes in addition to breast tissue, a practice Ehrenreich calls “the most savage form of breast cancer surgery” (p. 47). Overwhelming, feminist activists in the Women’s Health Movement were angry at the many tangible examples of how women’s bodies and health issues were neglected in the medical system. They were also angry at the deplorable way women as patients were treated in the male-dominated field of medicine, still enshrined in patriarchal ideology and paternalism (Potts, 2000). Rather than passively accepting a deeply sexist healthcare system, feminist activists of the Women’s Health Movement performed anger publicly, as much was in need of change within biomedicine.

As Kathleen Woodward (2009) records, much feminist theorizing of the 1970s and ’80s on emotion was concerned with legitimizing women’s anger. Feminists then were concerned with rearticulating what anger was and what it could do. If Freud understood anger to be male-identified, with violent anger in need of containment and regulation, feminists were actively appropriating anger in order to challenge a male-dominated society (Woodward, 2009, p. 56). In feminist theorizing of the 1970s and ’80s, as Woodward explains, “anger was explicitly understood as an emotion that is not only the basis for a group
but can also politicize a group, as an emotion furthermore that is *created* in a group, one that is enabling of action and not inhibiting of it” (pp. 55-56). Women’s public performances of anger, then, should be conceived of as politically motivated, rather than disregarded as individual outbursts of interior feeling more appropriately displayed in a private setting. As Naomi Scheman (1980) argued, “to become angry, to recognize that one has been angry, to change what counts as being angry becomes a political act” (as cited in Woodward, 2009, p. 49). As should be evident, at this particular moment in feminist organizing, it was essential that anger be understood as a political act. That women’s anger—specifically feminist anger—could be understood to have political utility and the potential to energize and motivate a public audience remains a key intervention brought forward by feminist theory of this period. As Elizabeth Spelman (1989) claimed: “There is a politics of emotion: the systematic denial of anger can be seen in a mechanism of subordination, and the existence and expression of anger as an act of insubordination” (as cited in Woodward, p. 49). When anger is expressed by women living under patriarchy, by the oppressed under the oppressor, anger becomes a distinctly feminist concern, Spelman (1989) argues. This is especially so because women’s anger has for too long been dismissed as nothing of consequence, trivialized and pathologized. Alison Jaggar (1989) argues that “anger becomes feminist anger when it involves the perception that the persistent importuning endured by one woman is a single instance of a widespread pattern of sexual harassment” (as cited in Woodward, p. 50). “Emotions,” Jaggar asserts, “become feminist when they incorporate feminist perceptions and values” (p. 50). Feminist theory of the 1970s and '80s articulated anger as an active and potentially motivating force for feminism—and for all oppressed women—yet Ehrenreich
(2001) finds little feminist sentiment—not to mention anger—in the mainstream of breast cancer culture at the turn of the millennium.

“Feminism helped make the spreading breast cancer sisterhood possible,” Ehrenreich (2001) admits, “and this realization gave me a faint sense of belonging” (p. 47). But this feeling of belonging was fleeting for Ehrenreich, as in breast cancer culture one website seamlessly links to another “from personal narratives and grassroots endeavors to the glitzy level of corporate and celebrity spokespeople” (p. 50). Ehrenreich comes to learn that in this world “cheerfulness is more or less mandatory, dissent a kind of treason” (p. 50) when, as an experiment, she posts a personal statement under the subject line “angry” on the Komen.org message board. In this post, Ehrenreich writes of her “heartfelt complaints about debilitating treatments, recalcitrant insurance companies, environmental carcinogens and, most daringly, ‘sappy pink ribbons’” (p. 50). Almost immediately, Ehrenreich is largely criticized by a group of women, also diagnosed and treated for breast cancer, for having a less than positive attitude towards her own cancer experience. “Suzy” writes to Ehrenreich to say, “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” (p. 50). “Kitty” is more forceful in instructing Ehrenreich to “run, not walk, to some counselling…Please, get yourself some help and I ask everyone on this site to pray for you so you can enjoy life to the fullest” (p. 50). Only terminally ill “Gerri” writes to say: “I am also angry. All the money that is raised, all the smiling faces of survivors who make it sound like it is o.k. to have breast cancer. IT IS NOT O.K.!” (p. 50). In fact, “Gerri” is the only woman online who dares to publicly affirm Ehrenreich’s angry message. At Komen.org, instead of anger, Ehrenreich finds cheerfulness pervasive in this online breast cancer culture.
cancer support group, and little to no mention of the politically charged dimensions of cancer causation, diagnosis and treatment, on the cultural politics of breast cancer survivorship.

The cheerfulness found in breast cancer support groups is but one part of a dominant breast cancer culture with its own distinct culture of emotion (Klawiter, 2008; King, 2006). Surely, as Ehrenreich (2001) argues, to blame the victim for this culture of emotion—the breast cancer patient in this instance—would be seriously misguided:

Scared and medically weakened women can hardly be expected to transform their support groups into bands of activists and rush out into the streets, but the equanimity of breast-cancer culture goes beyond mere absence of anger to what looks, all too often, like a positive embrace of the disease. (p. 48)

Ehrenreich refuses to blame frightened women, physically weakened by cancer, for refusing to rush to the streets. Yet it is not simply the absence of anger in support groups that is so distressing, it is what looks like a positive embrace of the disease that truly troubles her (p. 48). However, she notes that in feminist activist groups such as Breast Cancer Action—which purposefully critiques mainstream breast cancer culture—a very different view of the disease is put forward. “Like everyone else in the breast-cancer world,” Ehrenreich comments, “the feminists want a cure, but they even more ardently demand to know the cause or causes of the disease without which we will never have any means of ‘prevention’” (p. 57). A focus on cancer prevention not only provides a means of troubling the cancer problematic, it is also a response to the primary preoccupation of mainstream breast cancer culture with early detection and screening (Klawiter, 2008). As Ehrenreich explains:

Their emphasis on possible ecological factors, which is not shared by groups such as Komen and the American Cancer Society, puts the feminist breast-cancer activists in
league with other, frequently rambunctious, social movements—environmental and anticorporate. (p. 48)

Feminism, environmentalism, and anticorporate activism also share an affective economy of emotion—rambunctious yes, but also angry—with their broader calls for social justice.

As Ehrenreich (2001) states, feminist and environmental activists’ calls stand as “discordant voices in a general chorus of sentimentality and good cheer” (p. 48). Further, “breast cancer would hardly be the darling of corporate America if its complexion changed from pink to green” (p. 48)—which is to say from “business as usual” to environmentally focused cancer prevention strategies. For, as Ehrenreich stresses:

In the mainstream of breast-cancer culture, one finds very little anger, no mention of the possible environmental causes, few complaints about the fact that, in all but the more advanced, metastasized cases, it is the “treatments,” not the disease, that cause illness and pain. (p. 48)

Discordant feminist voices, then, refuse to diminish the fact that conventional biomedical treatments for cancer can be the cause of much physical and emotional pain. Experiences of enduring pain and suffering should not be obfuscated from a discussion of women and cancer; instead, they should be considered a central feminist concern.

In actual fact, one cannot enter into a relational discussion of feminism and anger, Sara Ahmed (2004) argues, without first considering a feminist history and the politics of pain:

Women’s testimonies about pain—for example, testimonies of their experiences of violence—are crucial not only to the formation of feminist subjects (a way of reading pain as a structural rather than incidental violence), but to feminist collectives, which
have mobilized around the injustice of that violence and the political and ethical demand for reparation and redress. (p. 172)

Whereas testimonies of pain are integral to feminism, one must not assume that pain provides the foundation for feminism; rather, feminism’s response to pain can be seen to transform it into a form of resistance. Ahmed insists: “The response to pain, as a call for action, also requires anger; an interpretation that this pain is wrong, that it is an outrage, and that something must be done about it” (p. 174). Anger, then, is a distinctly feminist response to pain, and when functioning as a form of resistance it is a way of transforming pain into something productive. Ahmed reminds of bell hooks’ argument that “simply naming one’s personal pain is insufficient and can easily be incorporated into the narcissistic agendas of neo-liberal and therapeutic culture” (Ahmed, p. 174). Ahmed explains that for hooks feminism can transform pain into politics only when it links to the “‘overall education for critical consciousness of collective political resistance’” (hooks, as cited in Ahmed, p. 174). Thus, Ahmed claims, while anger translates pain, anger is also in need of acts of translation in the public sphere (p. 175). “Feminism,” she argues, “as a response to pain and as a form of anger directed against that pain, is dependent then on acts of translation that are moving” (p. 175). If feminist anger must be translated into political action through concrete example, then disruptive breast cancer narratives can be understood to do this kind of political and cultural work in the public sphere, as Ehrenreich’s personal tract exemplifies.

4.3 Troubling Happiness

“Happiness,” Ahmed (2010) argues, “is consistently described as the object of human desire, as being what we aim for, as being what gives purpose, meaning and order to human life” (p.
1). She offers a compelling oppositional argument, saying: “I write from a position of sceptical disbelief in happiness as a technique for living well” (p. 2). The concept of happiness she refers to has been used as a means to justify oppression, and feminist, queer, and critical race scholarship has illustrated this in a variety of ways. Certainly, as Ahmed suggests, feminist critiques of “the happy housewife,” critical race critiques of “the happy slave,” or queer critiques of “domestic bliss” reveal the sexist, racialized, and heteronormative underpinnings of these representations (p. 2). “Around these specific critiques,” Ahmed argues, “are long histories of scholarship and activism which expose the unhappy effects of happiness, teaching us how happiness is used to redescribe social norms as social goods” (p. 2). She adds: “We might even say that such political movements have struggled against rather than for happiness” (p. 2). Feminism, to be sure, can be described as a struggle against this type of oppressively oriented “happiness.”

Ahmed (2010) asks, “Does bad feeling enter the room when somebody expresses anger about things, or could anger be the moment when the bad feelings that circulate through objects get brought to the surface in a certain way?” (p. 66). In other words, do feminists—in exposing instances of sexism, racism, homophobia, inequality, oppression or prejudice—produce these bad feelings? Whereas feminists potentially depress others by bringing up and making public unhappy topics, as Ahmed suggests, in so doing they actually expose the coercive mechanism by which happiness is maintained. Happiness can be maintained by ignoring or not speaking of difficult subjects. Ahmed rightly argues, then, that in this way “feminists do kill joy in a certain sense: they disturb the very fantasy that happiness can be found in certain places” (p. 66). In disrupting the fantasy that is happiness, happiness itself can be understood to be a precarious enterprise. “It is not just that feminists
might not be happily affected by the objects that are supposed to cause happiness but that their failure to be happy is read as sabotaging the happiness of others,” Ahmed says (p. 66). If the “feminist killjoy” is read as sabotaging the happiness of others by failing to properly embrace and perform happiness, presumably then the killjoy necessarily turns to negative affects like anger to effectively redirect the political mood.

Specifically pertinent to my argument, mainstream breast cancer culture has been identified as overwhelmingly shaped by positive affects and with calls for those diagnosed and treated for cancer to maintain a positive outlook, look cheerful, and appear happy (Ehrenreich, 2001; King, 2006; Klawiter, 2008). Samantha King (2006) minces no words, when she argues that mainstream breast cancer’s culture of survivorship inflicts a “tyranny of cheerfulness” (pp. 101-115) on those diagnosed and treated for breast cancer. Furthermore, King describes how in the current historical moment “breast cancer is widely understood as an enriching experience” (p. 101). She stresses:

While it is quite common for illness to function as a transformative experience on an individual basis, often in positive ways, the dominant discourse of breast cancer survivorship…leaves little room for alternative, less positive, understandings of the disease experience and its long-term effects, or, relatedly, of the political-economic context in which the fight against the disease is being waged. (p. 102)

If there is little room for less than positive accounts of the cancer experience—not to mention its long-term effects—cheerfulness can function as the only allowable personal performance of emotion within breast cancer culture. Thus, King argues,

Perhaps one challenge for those who seek to transform breast cancer culture, then, is to work against submersion in happiness and toward recognition of the deep and
fundamental problems that surrounds us, both within the realm of breast cancer and beyond. (p. 115)

Conversely, downbeat breast cancer narratives engage with rather than avoid the problems surrounding cancer and, in opposing the “tyranny of cheerfulness” (King, 2006), tell divergent stories of the cancer experience. Sociologists Emily Abel and Saskia Subramanian (2008) describe how “friends, relatives, and occasionally even acquaintances reassured newly diagnosed patients that they ultimately would find illness a blessing in disguise” (p. 122). Here, breast cancer is understood as more than an inadvertently enriching experience. In fact, the interviewees in Abel and Subramanian’s study resented being asked to mine their cancer experiences for lessons on how to live better: “Women repeatedly told us that they resented the pressure to use illness as an occasion for inner transformation,” even if they “welcomed the opportunity to reassess their lives” (p. 122). Whereas a cancer diagnosis may engender contemplation, the act of considering one’s life does not necessarily lead to fundamental change. “When a belief in the possibility of redemption through illness becomes a moral imperative,” Abel and Subramanian argue, “it infuriates rather than inspires” (p. 123). To be grateful for illness, then, is in keeping with the idea that good can emerge out of misfortune. Good, Christian teachings instruct, can arise out of personal suffering, pain and defeat (p. 122). “In the most extreme characterization, breast cancer is not a problem at all, not even an annoyance—it is a ‘gift,’” Ehrenreich (2009) says, “deserving of the most heartfelt gratitude” (p. 29). *The Gift of Cancer: A Call to Awakening*, written by a breast cancer survivor who believes cancer is a spiritual experience “makes you want to go out and get an injection of live cancer cells” (p. 29), as Ehrenreich sardonically remarks. In this narrative “cancer is your ticket to your real life. Cancer is your passport to the life you
were truly meant to live” (as cited in Ehrenreich, p. 29). “Cancer will lead you to God,” *The Gift of Cancer* insists (as cited in Ehrenreich, p. 29). “Let me say that again. Cancer is your connection to the Divine” (as cited in Ehrenreich, p. 29). In the logic of *The Gift of Cancer*, the moral imperative of cancer is beyond the material, bodily concerns of illness; in truth, cancer is a spiritual calling which might bring one closer to God.

Abel and Subramanian’s *After the Cure: The Untold Stories of Breast Cancer Survivors* (2008) flatly refutes cancer is any manner of a gift. Instead, their qualitative study investigates how women treated for breast cancer with chemotherapy and radiation—women who have been “cured”—cope with what their doctors do not take seriously: a host of ongoing health problems. This study contributes to a larger project contesting the discourse of survivorship, as it illustrates how “surviving” cancer is rarely easy or uncomplicated. The most common post-treatment symptoms women in Abel and Subramanian’s study reported were fatigue and cognitive impairment, both of which can only be known through patients’ narrative accounts of life after cancer (p. 3). In reality, Abel and Subramanian claim most of the women they interviewed experienced multiple symptoms simultaneously. “The more we listened to the women, the more we realized we might be hearing about a ‘post-breast-cancer syndrome’” (p. 3). “The accumulation of diverse symptoms often gave women the sense that their bodies and their minds were falling apart” (p. 3). Although the mass media are saturated with images of survivors “who are uniformly youthful (if not always young), ultrafeminine, slim, immaculately groomed, radiant with health, joyful, and seemingly at peace with the world” (King, 2006, p. 102), the women in Abel and Subramanian’s study tell a very different narrative of life after cancer treatment. This less than positive reality contradicts
myths Ehrenreich (2001; 2009) also encountered during diagnosis and treatment for breast cancer. She was told, for example:

You can defy the inevitable disfigurements and come out, on the survivor side, actually prettier, sexier, more femme. In the lore of the disease—shared with me by oncology nurses as well as survivors—chemotherapy smoothes and tightens the skin and helps you lose weight, and when your hair comes back it will be fuller, softer, easier to control, and perhaps a surprising new color. (Ehrenreich, 2009, p. 30)

But rather than emerge out of treatments and into survivorship transformed into a more beautiful version of themselves, the women in Abel and Subramanian’s study contend with the reality that breast cancer might function as a chronic condition. Moreover, “the disease can return at any time” and “watchful waiting and second-guessing one’s body never end” (p. 1). The cure provided by biomedicine, then, is always at least partially incomplete for the affective dimensions of watching and waiting for any sign of cancer’s return and a changed relationship to one’s body cannot be underestimated.

### 4.4 Troubling Survivorship

Contesting the discourse of survivorship—daring to perform an angry, disruptive breast cancer narrative—can entail a critique of the culture the post-treatment body is initiated into. Ehrenreich (2001) is particularly strident in her critique of the consumer-oriented nature of survivorship culture. She describes the mammogram which led to her breast cancer diagnosis as particularly onerous, not just because of its length but “because I had picked up this warning vibe in the changing room, which, in my increasingly anxious state, translated into: femininity is death” (p. 43). Here, Ehrenreich encounters “photocopied bits of cuteness and
sentimentality,” pink ribbons, a prayer festooned with pink roses, and, finally, in a free local weekly newspaper, a classified ad for a “breast cancer teddy bear’ with a pink ribbon stitched to its chest” (p. 43). This breast cancer bear is, Ehrenreich learns, but one of several distinct “species” of these creatures” (p. 46): “Bears are only the tip, so to speak, of the cornucopia of pink-ribbon-themed breast cancer products” (p. 46). Ehrenreich names a dizzying list of pink beribboned consumer items: sweatshirts, lingerie, aprons, rhinestone brooches, angel pins, scarves, caps, candles, coffee mugs, wind chimes, nightlights, even personalized cheques to pay for it all in the name of finding “the cure” (p. 46). “Awareness,” Ehrenreich says, “beats secrecy and stigma, but I couldn’t help noticing the existential space in which a friend had earnestly advised me to ‘confront mortality’ bore a striking resemblance to the mall” (p. 46).

This connection between mainstream breast cancer culture and consumer culture does not go unremarked for, as King (2006) says, “for better or worse, the history of the movement as a whole, and its successes and failures, cannot be understood apart from the corporate-driven, consumer-oriented philanthropic culture that emerged in conjunction with it” (p. xii). King explains:

While it would be easy to dismiss “pink ribbon” merchandise as a superficial and insignificant by-product of the upsurge in interest in the breast cancer cause, I prefer to approach it as a particularly prominent manifestation of the tight alliances that have formed between large breast cancer foundations and corporations, of the insidiously gendered nature of cause-related marketing that helps reproduce associations between women and shopping, and of a more general tendency to deploy consumption as a major avenue of political participation. (p. xxv)
Cause-related marketing—the breast cancer marketplace to be sure—reproduces gendered, sexist assumptions of what women want when it creates a space where women might participate in the political sphere only by shopping and consuming designated items. King suggests that enabling women to “shop for the cure” does instil a sense of participation, even if a slim margin of funds are dedicated to breast cancer related research and even less for prevention strategies. But retail consumption becomes an avenue for women to do something—anything—about the cancer problem, without having to engage in feminist politics (Ehrenreich, 2001) and protest the inherent sexism of pink ribbon cause-related marketing, or enter the grassroots fray of searching for the root cause or causes of the disease.

Even if unhappy breast cancer narratives expose the fact that women can experience several post-treatment symptoms, because “the cure” for cancer remains little better than chemotherapy, radiation and surgery, and these treatments are not without long term consequences, still women are instructed to be positive and hopeful upon diagnosis of cancer. The question of how to best cope with a cancer diagnosis becomes extremely problematic if from the start beating cancer is intrinsically tied to positive affects. Yet depictions of breast cancer survivors as cheerful, healthy, and spiritual are a relatively recent phenomenon; moreover, so too is the association of breast cancer and happiness. Abel and Subramanian (2008) write that “the cultural denial of both death and disability rendered breast cancer virtually invisible throughout much of its history” (p. 137). Education campaigns launched in the twentieth century aimed to replace negative images of breast cancer with positive ones, telling women that if they followed medical advice they could survive cancer, and go on to have normal, healthy lives (p. 137). “Now women can not just survive the disease; they can
go on to have even better, more profound existences” (p. 137). In the current historical moment, mainstream breast cancer culture is nothing if not completely upbeat. Now, positive thinking is understood to improve both body and soul, especially during cancer treatments.

Ehrenreich (2009) aims to dispel the “scientific” argument for cheer when she finds that positive thinking is reported to be the key to flourishing health: “There was, I learned, an urgent medical reason to embrace cancer with a smile: a ‘positive attitude’ is supposedly essential to recovery” (p. 33). A positive attitude, Ehrenreich explains, is understood to boost the immune system, “empowering it to battle cancer more effectively” (p. 34). “You’ve probably read that assertion so often, in one form or another, that it glides by without a moment’s thought to what the immune system is, how it might be affected by emotions, and what, if anything, it could do to fight cancer” (p. 34). In the 1970s the link between emotions, the immune system, and cancer was “cobbled together somewhat imaginatively” (Ehrenreich, p. 35). Whereas extreme stress can weaken the immune system, or parts of it, “it was apparently a short leap, for many, to the conclusion that positive feelings might be the opposite of stress—capable of boosting the immune system and providing the key to health, whether the threat is a microbe or tumor” (p. 35). A perfectly functioning immune system then, unencumbered by stress, was not only necessary for achieving great health, it was understood that it could even fight cancer. Instead, Ehrenreich chronicles how scientific study has proven that the immune system, designed to attack foreign invaders, does not adequately fight cancer cells—a cellular mutation, not an external invasion—“with the exception of those cancers caused by viruses, which may be more truly ‘foreign’” (p. 39). As Ehrenreich provocatively argues, reducing stress and cultivating positive thinking gave the breast cancer patient something to do during cancer treatment (p. 36). Now, “she had to
monitor her moods and mobilize psychic energy for the war at the cellular level” (p. 36). In this changing discourse of breast cancer, rather than simply submitting to cancer treatments women were instructed to help themselves by assuming responsibility for their mental health and to adopt positive thinking so they could help their bodies and immune systems fight cancer.

4.5 The Cancer Journals

In her reading of Audre Lorde’s work on racism, Ahmed (2010) says: “Lorde shows us, anger is visionary and the fear of anger, or the transformation of anger into silence, is a turning away from the future” (p. 175). As Lorde (2007) clearly argues in her various writings, anger is a necessary and just response to various oppressions and she theorizes anger in distinctly embodied and political terms:

My response to racism is anger. I have lived with that anger, ignoring it, feeding upon it, learning to use it before it laid my visions to waste, for most of my life. Once I did it in silence, afraid of the weight. My fear of anger taught me nothing. Your fear of that anger will teach you nothing also. (p. 124)

Here, Lorde makes a salient argument against fearing anger and thereby turning it into silence, arguing instead that it is wise to make productive use of it. For Lorde, anger is both visionary and forward looking; it is energetic and positive. As Lorde says, “anger expressed and translated into action in the service of our vision and our future is a liberating and strengthening act of clarification” (p. 127). To face the future, then, anger must be integrated into personal and collective responses to injustice and pain, for it engenders clarity and can be empowering. Furthermore, Lorde argues: “Every woman has a well-stocked arsenal of
anger potentially useful against those oppressions, personal and institutional, which brought that anger into being. Focused with precision it can become a powerful source of energy serving progress and change” (p. 127). Like Lorde, Ahmed understands anger to be a necessary feminist attachment and a potentially productive force in bringing about social change. Accordingly, Ahmed (2010) stresses that feminist anger involves reading how gender is inextricable from power relations, like race, class and sexuality, and how gender norms and heteronormativity function to regulate both bodies and social spaces (p. 176). Ahmed also notes that Lorde’s anger is not only salient in her response to racism but can also be readily identified in her personal writing on breast cancer.

Throughout *The Cancer Journals*, Lorde (1980) writes of the injustice a cancer diagnosis imparts and of her own cancer experience as a black, lesbian feminist. Lorde refuses to accept cancer as anything but a painful disease without redeeming qualities. She points out that “cancer is not just another degenerative and unavoidable disease of the aging process. It has distinct and identifiable causes, and these are mainly exposures to chemical or physical agents in the environment” (p. 73). Here, and elsewhere in *The Cancer Journals*, Lorde argues that cancer should not be framed as the individual responsibility of the cancer patient. Overwhelmingly, she argues that cancer must have some link to a polluted environment and, if this is the case, preventing cancer must become a collective responsibility. Despite evidence to support this finding, Lorde argues that in the late 1970s the American Cancer Society refused to recognise the environmental aspects of cancer causation:

Any holistic approach to the problem of cancer is viewed by ACS with suspicion and alarm. It has consistently focussed upon treatment rather than prevention of cancer,
and then only upon those treatments sanctioned by the most conservative branches of western medicine. (p. 71)

Here, Lorde calls for a holistic approach to the cancer problematic by integrating environmental factors into an understanding of cancer causation, as well as calls for the integration of viable holistic healing options into cancer treatments.

Because the ACS refused to recognize or investigate a potential connection between cancer and the environment, Lorde (1980) argued that women, especially in light of rising breast cancer rates, must arm themselves with as much information as possible regarding their own health. She urges that “we owe ourselves this information before we may have reason to use it” (p. 73). This is all the more necessary, Lorde argues, because “the ACS and its governmental partner, the National Cancer Institute, have been notoriously indifferent, if not hostile, to the idea of general environmental causes of cancer and the need for regulation and prevention” (p. 71). If governmental agencies will not sufficiently protect women from cancer, then collectively women must seek ways to do this for themselves. Women must educate themselves and remain vigilant for, as Lorde reminds us, “we live in a profit economy and there is no profit in the prevention of cancer; there is only profit in the treatment of cancer” (p. 71). To refuse to validate cancer prevention research which may implicate a polluted environment is truly insidious, Lorde argues, recognizing that in a profit-driven economy there is money to be made only in developing new and better cancer treatments. Yet cancer prevention is essential in order to reduce, if not eliminate, the number of women whose bodies and minds are forever changed by breast cancer.

Without a doubt, cancer changes women’s lives for the worse, not the better, Lorde argues throughout The Cancer Journals. After Lorde is forced to undergo mastectomy, a
decision she understands as choosing her life over her breast, she is visited by a volunteer from the Reach for Recovery Program. The volunteer, a breast cancer survivor and herself post-mastectomy, endeavours to assist Lorde in her transition to life after surgery. The volunteer’s strategy, however, is to convince Lorde that she can be just like new. The volunteer argues that with the use of a prosthesis to hide her lost breast, Lorde might remain attractive to men and her children need not be ashamed of her. Reflecting on this, Lorde says:

As a 44 year old Black Lesbian Feminist, I knew there were few role models around for me in this situation, but my primary concern two days after mastectomy were hardly about what man I could capture in the future, whether or not my old boyfriend would still find me attractive enough, and even less whether my two children would be embarrassed by me around their friends. (p. 56)

Without role models and lacking the precise language, the courage even, to say that she loves women, Lorde keeps silent about her sexual orientation. She does not say out loud that she is neither worried nor concerned about men’s attention and that this is the least of her concerns two days post-mastectomy. Lorde later reflects that “there still appears to be a conspiracy on the part of Cancer Inc. to insist to every woman who has lost a breast that she is no different from before…that nothing has happened to challenge her” (p. 62).

The assumption that women should strive to become the same as before—that they have not been challenged by cancer to their very core—and that a prosthesis is the same as the breast that was once in its place—engenders a livid anger in Lorde. She refuses a prosthesis lest it be assumed she is striving to be the same as before, and instead allows herself to be forever changed by cancer and visibly marked. Lorde argues that somehow, even in the wake of mass use of prostheses, women who have had to undergo mastectomies
should become visible to each other (p. 61). However, as Lorde learns, to refuse any prosthesis after mastectomy is to essentially challenge the cancer establishment, which is rarely tolerated, and will not go unremarked upon. When Lorde visits her surgeon’s office post-mastectomy she is reprimanded rather than simply tolerated—not to mention respected—for her refusal to wear a prosthesis. The receptionist, whom Lorde otherwise admired for her kind, no nonsense demeanour, devastates Lorde when she tells her that her presence without a prosthesis is bad for the “moral” of the office. Lorde remembers, “I was too outraged to speak then, but this was to be only the first assault on my right to define and to claim my own body” (p. 59). Lorde stresses that she does not remain unchanged by cancer; she is forever marked and bears scars as proof:

My scars are an honourable reminder that I may be a casualty in the cosmic war against radiation, animal fat, air pollution, McDonald’s hamburgers and Red Dye No. 2, but the fight is still going on, and I am still a part of it. (p. 60)

Instead of purporting to be somehow even better than before after her mastectomy, Lorde says: “I refuse to have my scars hidden or trivialized behind lambswool or silicone gel” (p. 60). Always, Lorde accepts her own anger as a legitimate and powerful response to injustice, and here this anger is directed at the cancer establishment as the disease is suspected to be human-made.

In arguing that cancer is unjust, painful, and life-altering, Lorde (1980) can also be understood to critique the cultural politics of happiness. She engages with the cultural politics of emotion in questioning the appropriate attitude one should adopt in order to prevent cancer, as well as in order to cope with cancer treatments:
The idea that the cancer patient should be made to feel guilty about having had cancer, as if in some way it were all her fault for not having been in the right psychological frame of mind at all times to prevent cancer, is a monstrous distortion of the idea that we can use our psychic strengths to help heal ourselves. (p. 74)

Whereas Lorde acknowledges that the right psychological frame of mind may help one to cope, she rejects the idea that a questionable emotional state of mind will allow cancer to take hold. Whereas Lorde can accept that the mind may have power in helping to heal the body, she does so without accepting “happiness” as the only emotion conducive to healing.

It was very important for me, after my mastectomy, to develop and encourage my own internal sense of power. I needed to rally my energies in such a way as to imagine myself as a fighter rather than as a passive victim suffering. At all times, it felt crucial to me that I make a conscious commitment to survival. (p. 74)

While Lorde makes a commitment to survive, that does not mean she simply ignores the negative reality of cancer. Lorde insists that “a clear distinction must be made between this affirmation of self and the superficial farce of ‘looking on the bright side of things’” (p. 74).

Too often, looking on the bright side of things requires a commitment to not get angry, to ignore anything worthy of anger. Lorde correctly says:

It is easier to demand happiness than to clean up the environment….Let us seek ‘joy’ rather than real food and clean air and a saner future on a liveable earth! As if happiness alone can protect us from the results of profit-madness. (p. 74)

In fact, the cultural demand for happiness acts as part of a coercive politics that disapproves of anger as a legitimate response to injustice. Lorde asks then, if only rhetorically:
Was I wrong to be working so hard against the oppressions afflicting women and Black people? Was I in error to be speaking out against our silent passivity and the cynicism of a mechanized and inhuman civilization that is destroying our earth and those who live upon it? Was I really fighting the spread of radiation, racism, woman-slaughter, chemical invasion of our food, pollution of our environment, the abuse and psychic destruction of our young, merely to avoid dealing with my first and greatest responsibility—to be happy? (p. 75)

Here, Lorde refutes the idea that happiness is something to aspire to at all costs. She refuses to aspire to happiness if it requires ignoring, or worse yet bright-siding, the very real oppressions of others. Lorde stresses that the only truly happy people she has met are those who recognize and engage in the fight against injustice and oppression (p.75). Too often, instead of fighting for better treatment of the earth and working to find ways to prevent cancer, attaining happiness becomes the only goal:

If the achievement and maintenance of perfect happiness is the only secret of a physically healthy life in America, then it is a wonder that we are not all dying of a malignant society. The happiest person in this country cannot help breathing in smokers’ cigarette fumes, auto exhaust, and airborne chemical dust, nor avoid drinking the water, and eating the food. (p. 75)

Furthermore, “the idea that happiness can insulate us against the results of our environmental madness is a rumour circulated by our enemies to destroy us” (p. 75). Happiness, then, is actually cloaked in a cultural politics that demands that injustice be ignored, anger denied, and a constant bright-siding be in effect.
Throughout feminist theorizing it is anger, not happiness, which is figured as a productive, political force in the public sphere. It is anger, and not happiness, which functions as a powerful response to pain. “Anger,” Ahmed (2004) argues, “is creative; it works to create a language with which to respond to that which one is against, whereby ‘the what’ is renamed, and brought into a feminist world” (p. 176). Ehrenreich and Lorde critique the mainstream cultural politics of breast cancer, describing it as coercively normative, emotionally manipulative even. In Ehrenreich’s and Lorde’s writing the mainstream of breast cancer culture is brought into a feminist world, and is criticized for its emotional culture of cheerfulness bordering on a pursuit of happiness at any cost. As Ehrenreich (2001) sums up, in the mainstream of breast cancer culture, “the stance toward existing treatments is occasionally critical…but more commonly grateful; the overall tone, almost universally upbeat” (p. 48). But Ehrenreich is neither grateful, nor upbeat, about cancer or its treatments. Cancer, she says unequivocally, is nothing short of an abomination. Lorde (1980) also refuses to adopt an optimistic attitude, when she too is encouraged to bright-side her cancer experience. Instead, Lorde asks: “What would happen if an army of one-breasted women descended upon Congress and demanded that the use of carcinogenic, fat-stored hormones in beef-feed be outlawed?” (p. 16). Feminist anger, however, is generally not well tolerated in the public domain (Ahmed, 2004, p. 177). Angry women are too often publicly dismissed as irrational, misguided, and even crazy. Despite this, Ehrenreich and Lorde both choose to act out, in order to illustrate how breast cancer is a feminist concern worthy of anger.

Kathleen Woodward’s (2009) theorizing of the cultural politics of emotion is informed by Freud’s structuring of affects, yet she acknowledges that Virginia Woolf’s *Room of One’s Own* provides a “primary textual touchstone” in understanding feminist anger
This conception of affect is very much in response to a psychological understanding of emotion, where feelings are seen as deeply private and hidden within one’s interiority, so much so that they are unknowable even to oneself (p. 21). But Woodward stresses that there need not be a “contradiction between the psychological emotions that have their origin in the self (grief would be such an example) and the social emotions that have their origin in a group (feminist anger would be an example)” (p. 23). After all, the current historical moment is indicative of a “mixed economy of feelings” (Woodward, p. 25), and narrating personal experience has a crucial function since it is through narrative that “emotion can be intensity recognized, redescribed, and owned as if for the first time” (p. 25).

The pivotal scene in Woolf’s text where the narrator “attends to the emotional experience of her own spontaneous anger” (Woodward, 2009, p. 7), which is “transparently available to her,” illustrates how differently Woolf’s and Freud’s—feminist and psychoanalytic—understandings of anger can be. Woolf honours her narrator’s emotional experience: “She doesn’t consider her anger ‘hysterical’ or a screen for something else but rather values it and seeks to understand the reasons for it” (Woodward, p. 7). Here, anger is rendered as having an epistemological edge, disclosing how Woolf’s character is entrenched in unequal power relations (p. 7). Anger, feminist theory and praxis illustrates, is most generative when understood as a political emotion, even if it is a deeply personal one as well. Feminist theorists have shown how emotions “shaped by cultural norms and practices, can be collective as well as personal, thus underscoring the mutually constitutive nature of subjectivity and sociality” (Woodward, 2009, p. 21). In articulating a cultural politics of emotion, Woodward’s method of reading autobiographical texts draws on a critical phenomenology of emotions and necessarily places them in social and historical contexts (p.
Having worked in a similar manner, I will now move from a reading of Ehrenreich’s and Lorde’s disruptive breast cancer narratives to Conway’s, as she struggles to make sense of and accept her own anger.

4.6 Ordinary Life

Kathlyn Conway’s (1997) *Ordinary Life: A Memoir of Illness* refuses to turn away from the intense difficulties cancer can evoke. Conway was a graduate student at Harvard when diagnosed with Hodgkin’s disease; in her forties and a working mother with two children when diagnosed with breast cancer; and, then, a year after breast cancer treatments ended, she was diagnosed with lymphoma. “I feel like a modern phenomenon—,” she says, “a forty-seven-year-old woman with one husband, two children, and three cancers” (p. 1). Conway’s breast cancer narrative is not about learning life lessons or coming to the understanding that cancer may be a means of positively transforming one’s life. Her story is a decidedly unhappy one. For Conway, cancer cannot be made into a positive occasion; it is something one must simply learn to tolerate: “I have maintained that the experience of cancer is without redeeming value; that I have not been transformed by the experience; that it is, beyond all else, a misery to be endured” (p. 1). In refusing the first time to understand cancer as an occasion for a transformational experience, after the third cancer Conway is positively resolute: “I am still convinced that cancer is not transformative, that the trauma did not make me a better person” (p. 2). Conway, a practicing psychotherapist, is aware that a happy, transformative story is what others want to hear when they ask about her cancer experience. Conversely, Conway says, “I set out to write the truth about my cancer while I was still in its grip” (p. 253). She adds: “I was passionate in my resistance to telling the story that other
people seemed to want to hear—of lessons learned, of cancer as a transformative experience” (p. 253). She refuses to narrate her cancer experience in *Ordinary Life* as a story to please others. Conway is angry, and she is especially angry at the expectation that she should tell a redemptive, positive version of having had cancer not once, but three times.

Anger, in all its dimensions, is of value, Conway (1997) claims; in the afterword reviewing the narrative she constructs in *Ordinary Life*: “It’s not my anger that I mind. I’m proud of my anger, at least when it’s clean and direct, a response to injustice” (p. 254). In finding much anger in her own narrative, Conway does not recoil from it because: “I was showing that breast cancer is also this: feeling so horrendous and beaten up that you can neither fight nor demand that the world pay attention; you can only get through it barely and ignobly” (p. 255). Conway admires a politicized anger, a response to injustice, and admits her own anger was often brought about in a struggle to simply get through cancer treatments: “It’s difficult to accept how mean spirited and lost I felt when I spoke from inside my illness” (p. 254). In speaking from inside cancer, Conway does not sugar-coat the experience. In so doing, she does not obscure the fact that her anger was not just directed at the injustice of a cancer diagnosis but directed at those closest to her: the doctors and nurses who fought to save her life, friends, and family. But this misdirected anger, she says, in time would pass: “Only my anger at the threat to my life survived, and I held onto it for dear life” (p. 256). This deep anger, Conway maintains, was essential in her survival from breast cancer.

When Conway (1997) goes in for a routine mammogram she hopes she will later regard it as an unnecessary procedure, but says she has “never been known to look on the bright side” (p. 27). Having already had cancer some twenty years before, she is unable to shake a fearful feeling when waiting for the biopsy results. Because she cannot simply look
on the bright side of things, she asks, “Why can’t I hide my feelings better?” (p. 27). When she is diagnosed with breast cancer, Conway is instructed in subtle, and not so subtle ways, how to be a “good” patient. Friends, family, acquaintances, even total strangers all have a cancer story they want to share with her. “The stories others told often seemed to contain a message for me” (p. 2) and, often the message was blatantly obvious: “When I heard the story about an eighty-year old woman who survived four cancers, I felt that I had better be optimistic and survive” (pp. 2-3). Optimism in these stories is understood not only as the key to survival, but also necessary in order to endure the various cancer treatments. But “When I was told of people who suffered through miserable treatments only to die, I was at a loss as to the point” (p. 3). Conway is unable to forget just how miserable and painful breast cancer had been, and in writing her own breast cancer narrative she found she was finally able to be honest in way conversation did not allow, because others indicated they only wanted to hear the positive parts of her experience (p. 2).

The standard treatments for breast cancer, mastectomy and chemotherapy, prove almost too much for her to bear. While in hospital recovering from surgery and waiting for medical attention, Conway (1997) is first left feeling helpless, and then becomes very angry.

The pain increases and I ring the bell for a nurse. Nothing. I wait. I ring again. When a nurse finally comes, I request pain medication. She promises to bring some but does not return. No one comes. I ring and wait, again and again. Finally a nurse brings some Demerol. And I sleep for a while. I wake because I need to go to the bathroom, and I call the nurse to help me out bed. No one comes. I feel helpless and angry, but mostly helpless. Finally, a male nurse’s aide peers through the curtain at me, looking annoyed. I explain that I need help getting to the
bathroom, and he tells me that they are very busy. I will have to go by myself. If I fall, I should call them. (p. 79)

Here, Conway is left to her own devices, even when getting to the bathroom, coping alone with the pain and immobility her mastectomy has inflicted. This situation leaves Conway feeling angry at those in charge of attending to her post-surgery care, because she experiences the brunt of inattentive, and likely overworked, nurses who consider her but one of the many patients they are in charge of caring for that day. Understandably, Conway wants more personalized and compassionate post-surgical hospital care. Yet these feelings of pain and helplessness are nothing compared to the voracity of the anger she experiences—to her surprise—when reading an article in MS magazine while recuperating from surgery. The article features women who speak openly about breast cancer, its attendant treatments and surgeries, and make no attempt to disguise their bodies in cancer’s aftermath.

Conway (1997) is surprised when she recoils from public displays of cancer’s disfigurement, saying: “I consider myself a feminist who believes in political action. So why am I put off by this public movement?” (p. 111). For Conway, losing a breast to cancer and then her hair during chemotherapy does not leave her feeling empowered, let alone proud. “I doubt that I could proudly show my scars or my bald head. I feel sad, not proud” (p. 111). Scars and baldness are to be endured, not publicly celebrated, in Conway’s worldview. She is simply unable to support this manner of public protest, let alone go without breast reconstruction after mastectomy or refrain from wearing a wig in public. “I’m trying to mourn my losses and accept the damage that has been done to my body. I need to do this in private, and wigs and reconstruction may afford some privacy” (p. 111). On the other hand, she is angered by other breast cancer patients who believe that they can somehow avoid what
she has had to endure: mastectomy and chemotherapy as well as discomfort, pain, and sadness. When she accompanies a fellow breast cancer patient who intends to buy a wig before undergoing chemotherapy, the acquaintance decides in the end not to buy one, explaining her wilful resolve not to lose her hair. Conway encounters this sentiment several times in other patients. “I am hurt and angered by the indifference of these women to my feelings,” she says, “and by their presumption that, through an act of will, they can avoid what I couldn’t” (p. 205).

As a result of these experiences, Conway (1997) searches for narratives which might more accurately reflect negative feelings towards cancer. Instead, she finds few downbeat breast cancer stories and instead becomes increasingly resentful at “glib, cute stories” that inform her that cancer is not so bad (p. 193). In particular, she says, “I hate hearing that cancer has made someone a better person” (p. 193) because “It’s only making me a worse person” (p. 193). It reassures Conway that she is not alone in her anger when she meets one woman who does not attempt, in any way, to suggest that cancer is not so bad. For her, cancer, understandably, is the worst thing that could have happened to her, and she tells a downbeat story of long waits and indifferent doctors as she contemplates chemotherapy knowing that it will likely cause infertility (p. 112). Still, for Conway, claiming her own disruptive breast cancer narrative is difficult and “this is not the story I would have chosen to tell had my cancer led to my death” (p. 253). “This is not the memorial I would have preferred to leave behind, nor is the morose, self-centred woman I describe the mother I would want my children to remember” (p. 253). “In short,” Conway says, “this is a difficult story to own” (p. 253).
Certainly, Conway’s (1997) anger is not limited to the medical establishment; her family, becomes its prime target. Conway’s husband, David, although supportive, paradoxically, angers her.

Although I am conscious of how much I love David, I communicate nothing but rage. I greet him with my litany of complaints; I show no interest in his day; I am angry at him for everything. He does the shopping, but the bananas are too big, not ripe, too ripe. He bought too much lettuce and not enough milk; he forgot to call his parents. David is afraid to speak for fear of saying something that will set me off. I feel abandoned, and then I am furious at him for withdrawing. (p. 192)

David, it seems, can do no right by Conway. She is angry when he does something and angry too when he neglects to do something. Understandably, David withdraws from Conway’s accusations which, in the end, makes her even more furious. Throughout Conway’s narrative David is shown to be a loving and supportive partner, but when she is diagnosed he identifies with Conway’s cancer so much so she has to remind him this is her disease to endure, not something they can truly fight together. Eventually, David comes to understand he must find a way to take on a supporting role even if that means withdrawing.

As much as David’s coping mechanism for dealing with Conway’s anger is to withdraw from her, she too begins to withdraw from family life. Conway (1997) claims she must do this in order to protect both her husband and her two young children:

When David is at home, I make myself scarce to protect the children from my wrath; but then I think of my patients whose depressed mothers stayed in their rooms, leaving their children feeling abandoned and angry, and I worry. (p. 192)
Conway understands that simply withdrawing from family life is not a solution to her anger; nonetheless, the force of her anger is fierce and unabated. For now, withdrawal is the best temporary solution because, she says, “I feel myself unravelling completely. The children are caught up in our nightmare. We snap at them. They snap at us and at each other. We have no patience. We spend little time with them except to issue orders” (p. 193). Conway’s anger eventually fades, but only when she regains a margin of good health. And when she has clarity she realises that, in reality, she is depressed. She explains that she wrote *Ordinary Life* as a way to process her depression at a time when she was feeling overwhelmed and extremely sad. She states several times in this disruptive breast cancer narrative that cancer is not making her a better person, but a worse one. It is almost as if her feelings of depression are tied to the sentiment of having “failed” at having cancer, because for Conway there is no personal transformation, spiritual enlightenment, or epiphany. She does not come to understand cancer as a meaningful life lesson. Instead, along with the depression that comes in cancer’s aftermath is the painful reality that her relationship with her family is profoundly and perhaps irrevocably changed:

I still keep myself at a slight distance from David, Zach and Molly, sometimes refraining from expressing my love because to do so seems to bring pain along with it, a reminder of how afraid I am of losing them or of their losing me. (p. 263)

She describes this withdrawal as the most painful, depressing aspect of cancer’s aftermath. “This is the worst legacy of my illness—that I sometimes avoid knowing how deeply attached I am to them” (pp. 263-64). Here, perhaps it is that Conway refrains from *showing* how deeply she is attached to her family, rather than a refusal to *know* this. But the act of
writing her story seems to facilitate a way of understanding her deep attachment to family, not to mention both anger and grief.

Ahmed (2004) argues that anger’s creative power lies in its ability to create a language to articulate that which one is against. This process, she says, is dynamic and evidenced in the diverse way feminists name what they are against (p. 176). “Different feminists construct the ‘object’ of anger quite differently, in ways that are in tension, although they share connections in the ‘directionality’ of the emotion” (p. 176). To be sure, Ehrenreich (2001), Lorde (1980), and Conway (1997) express anger divergently from one another. They also differ in the specificity of what their object of anger is. In doing so, they seemingly argue for what women with breast cancer should be angry about, with each woman articulating and performing anger with her own particular investment in responding to the cultural politics of breast cancer. Although Ehrenreich, Lorde and Conway are invested in their individual arguments, these arguments do not in turn become prescriptions for others on how to live with cancer. Perhaps anger, unlike happiness, does not exert a coercive, prescriptive politics. Ahmed reminds us that having an engaged stance requires that feminists not block the anger of other feminists: “How feminists receive the anger of other feminists is a question about the conditions in which it is possible for just hearings to be translated into action” (p. 178).

However, reading feminism as a form of anger—and feminists as angry—also provides the conditions by which feminist claims might be dismissed. “Rather than responding by claiming that feminism is not motivated by anger (which would accept the problematic distinction between anger and reason),” Ahmed (2004) says, “we can think instead about anger as a speech act, which is addressed to someone” (p. 177). Anger then, as
Ahmed suggests, can be understood as performative and, I would argue, an important context-specific performance. As Marilyn Frye (1983) argues

> Being angry at someone is somewhat like a speech act in that it has a certain conventional force whereby it sets people up in a certain sort of orientation to each other; and like a speech act, it cannot ‘come off’ if it does not get uptake. (as cited in Ahmed, 2004, p. 177)

This idea of anger as performative is engaged with by Brenda Silver (1991), who argues that the anger of the original speaker can provoke “the anger of the person who attempts to silence the upstart through an act of linguistic fiat” (cited in Ahmed, 2004, p. 177). In this way, anger can lead to a kind of impasse and can function to shut down communication rather than encourage it. As both Frye and Silver suggest, anger as a political act does not always get received under conditions where it might receive a just hearing (Ahmed, p. 177).

Nevertheless, Ahmed argues that feminists must “persist in explaining why our anger is reasonable, even in the face of others who use this anger as evidence of poor reason” (p. 177). “Making public statements, getting heard, writing banners: these remain crucial strategies for feminism, even when they fail to get uptake” (p. 177). Writing angry disruptive breast cancer narratives, as Ehrenreich, Lorde and Conway have done, are also important feminist interventions in public discourse, even if they are initially misunderstood or heretofore have failed to receive adequate public attention.

### 4.7 The L Word

I would like to touch upon a final angry breast cancer narrative here, one that shifts the terrain from a feminist politic to a lesbian, trans and queerly articulated one, and at the same time
from autobiography to fiction. In the fictional world of Showtime’s lesbian drama, *The L Word*, Dana, a professional tennis player, is diagnosed with breast cancer while training for a big match. Although Dana is young and otherwise healthy, she will not survive a breast cancer diagnosis. This is not a story of victorious survivorship—it is a downbeat breast cancer narrative with an unhappy ending. What is more, *The L Word* opts for an incredibly quick conclusion to Dana’s disruptive cancer narrative, as before the end of Season Three she has already succumbed to complications. Almost immediately upon diagnosis Dana is portrayed as a “bad” cancer patient. When Lara, Dana’s girlfriend, finds a lump in Dana’s breast, Dana dismisses it as nothing to be concerned about. When Lara insists that the lump be examined by a doctor and even makes Dana an appointment, she promptly forgets to go in. Dana still treats the lump, and a visit to the doctor, as mere annoyances. When the mammogram reveals that the lump is suspicious and she must undergo a fine needle biopsy, Dana’s mood changes; now, she is a little worried. When what is assumed to be a benign lump is biopsied and found to be cancerous, Dana is scheduled for surgery. The surgeon finds the cancer has metastasized, she must undergo mastectomy, and muscle will be removed because cancer has already spread to her lymph nodes. Now, Dana surmises, her tennis career—and life—is over.

At each turn, Dana does not perform as a “good” or obedient cancer patient should, as she refuses to adopt a positive attitude towards cancer. During chemotherapy she becomes angry and despondent. First, she finds that when the chemotherapy hits her bloodstream it is too cold and uncomfortable. She tells the attending nurse something must be wrong. Lara asks Dana a few minutes later how it now feels: “How the fuck do you think it feels, Lara? To have everything under the kitchen sink pumped into your veins. My skin is fucking
crawling.” “Where the fuck did my life go?” Dana asks. Dana’s negative attitude, her fear that she is dying, not to mention her angry lashing out, make her decidedly unpleasant to be with. When Lara bakes a cake to celebrate Dana’s first chemotherapy treatment, Dana explodes. She rebukes Lara’s efforts to cheer her up, to improve her attitude towards cancer, and refuses a piece of cake, saying she feels too nauseated to eat. When Dana retreats from the party to lie down, Lara turns to Dana’s friend, Alice, an ex-girlfriend, saying, “I don’t know how to deal with this, Alice. This anger in her. It’s nothing I’ve even seen before.” “Well,” Alice answers, “she’s never had cancer before.” Even if the happy, hopeful, positive cancer scripts are already written, the angry cancer patient cannot bear to mouth the words. Indeed, Dana embodies what I call the “cancer killjoy,” inspired by Ahmed’s articulation of the “feminist killjoy,” illustrating a cultural performance I will explore next in Chapter Five.

Overwhelmingly, Dana’s breast cancer narrative is a decidedly angry and unhappy one. She pushes her girlfriend away, and finally Lara does leave. In the end, Dana’s health deteriorates quickly and she dies alone in hospital. The storyline purposefully ends in tragedy, with Dana’s death. One might question the utility of introducing the largely underrepresented storyline of a lesbian with breast cancer, only to kill off this character in less than one television season. One might even question the political utility of telling unhappy queer stories, a theme I take up and address throughout this project. Ahmed (2010) urges that unhappy endings in fictionalised queer worlds need to be reconsidered: “We are not obliged to ‘believe’ in the unhappy ending by taking it literally as ‘evidence’ that lesbians and gays must turn straight, die, or go mad” (pp. 88-89). She insists that reading unhappy queer endings is a complicated endeavour (p. 89): “A literal reading suggests that the very distinction between happy and unhappy endings ‘works’ to secure a moral distinction
between good and bad lives” (p. 89). When reading depictions of unhappy queer lives, the reader must participate in “an active disbelief in the necessary alignment of the happy with the good, or even in the moral transparency of the good itself” (p. 89). “Rather than reading unhappy endings as a sign of the withholding of moral approval for queer lives,” Ahmed argues, “we must consider how unhappiness circulates within and around this archive, and what it allows us to do” (p. 89).

In *The L Word*, Dana’s unhappy breast cancer narrative plays out in direct relation to another character’s transition narrative. Max, born Moira, begins transitioning from female to male at the time of Dana’s cancer diagnosis. Ahmed’s (2010) suggestion that unhappiness circulates and that an unhappy queer ending might provide an opportunity for rereading seems especially apt here, because while Dana’s breast cancer narrative ends unhappily, Max’s narrative does not. Although he is frustrated that his transition process is slower and more expensive than he first imagined, it is worth the investment both of time and money. Both characters imagine how their lives will be transformed by the physical changes done to their bodies. In a parallel sequence, Dana stands in front of the mirror cupping and holding one breast, seemingly trying to imagine what her chest will look like after surgery. Similarly, Max binds his breasts with gauze and then stands in front of the mirror inspecting his masculine contours. Here and elsewhere, the parallel aspects of Dana’s and Max’s narrative trajectories are deliberate rather than coincidental. Controversially, *The L Word* wants to emphasise the connection between Dana and Max: as Dana’s health declines, Max’s transformation into a new life emerges. It would be too easy, then, to read Dana’s death as an example of either the moral decrepitude of queer lives or the immorality of the “bad” patient who rages against cancer. Instead, an examination of Dana’s unhappy demise and Max’s
somewhat happy entry into a new life might provide the opportunity not only to examine queer body politics in relation to breast cancer, but also to make space for discussions of death and dying within breast cancer culture. In the next chapter, I will turn to performances of cancer survivorship in documentary film and query these performances of cancer survivorship; in so doing, I will explore the “cancer killjoy” in greater detail.
5 Claiming the Cancer Killjoy: Situating *Chasing the Cancer Answer* and *Crazy Sexy Cancer*

5.1 Chasing the Cancer Answer

*Chasing the Cancer Answer* (2007) is a response to Canadian Cancer Society’s statistics which reflect almost one in two Canadians will be diagnosed with cancer. As journalist Wendy Mesley says in her opening statement, “I can accept that I have cancer. What I can’t accept is that it’s so common.” She wants to uncover why cancer rates in Canada, not to mention elsewhere in the Global North, are so alarmingly high. *Chasing the Cancer Answer* argues that cancer rates have reached epidemic proportions, and something must be done about it. In search of answers, Mesley is not afraid to ask hard-hitting questions of cancer establishment leaders, pharmaceutical company representatives, and treatment specialists. She also speaks with cancer patients and their families, pathologists, and environmental activists committed to preventing cancer. Originally aired as a special report for MarketPlace, *Chasing the Cancer Answer* has been rebroadcast on the Canadian Broadcasting Corporation and is now distributed through CBC Learning. In this chapter, I will explore why *Chasing the Cancer Answer*, although deemed to be of educational value, is declared by *Globe and Mail* columnist Margaret Wente (2006) to provide “No Answer.” I would like to explore how Mesley, in presenting a disruptive narrative of cancer, becomes the embodiment of bad news. As such, I will explore Sara Ahmed’s (2010) conception of the “feminist killjoy” and the crucial role this figure performs in critiquing the politics of happiness; in so doing, I would like suggest the critical utility of positively claiming the “cancer killjoy,” a necessarily disruptive figure within breast cancer culture. Then, I will explore *Crazy Sexy Cancer* (2007),
a documentary which bills itself as performing a different kind of cancer story, but can be read instead to subscribe to a normative embodiment and performance of survivorship.

5.2 The Cancer Killjoy

Mesley (2006) takes issue with the Canadian Cancer Society’s official position, “Seven Steps to Health,” which claims that eating a healthy diet of fresh fruit and vegetables, getting exercise, staying out of the sun, and not smoking is a sufficient cancer prevention strategy. “Tell me something I don’t know!” she says. “That does not explain why cancer is still increasing.” Mesley challenges the CCS by refusing to ignore evidence that points to how a number of allowable environmental chemicals may act as potential human carcinogens. Indeed, Mesley takes issue with the CCS’s minimization of environmental toxicants, which in their literature are described as only responsible for a possible five to ten percent of all cancers detected. Instead, the CCS reminds Canadians to avoid handling hazardous materials at home and work, to see their doctor regularly, and to follow cancer screening guidelines. In Chasing the Cancer Answer’s opening segment, Mesley undergoes a blood test in order to screen for possible environmental chemicals in her bloodstream. She assures viewers she does not believe a blood test will reveal why she got cancer, yet, it reveals that Mesley tests positive for 44 out of a possible 57 toxic heavy metals and chemicals. Nickel, arsenic, benzene, cadmium, organochlorine pesticides and PCBs are all found in Mesley’s blood, some in unusually high levels. As she says, “I’m full of carcinogens. And apparently that’s normal.” Mesley wants to know why the Canadian Cancer Society, a patient advocacy group that informs government, does not warn the public of suspected chemical carcinogens and
how best to avoid them. As she recounts, following the CCS’s “Seven Steps to Health” did not prevent her—and so many other Canadians—from developing cancer.

Crucially, Mesley questions the motivations of the CCS’s cancer prevention strategy which educates the Canadian public to assume personal responsibility for controlling individual lifestyle factors. In Windsor, Ontario, Mesley discusses the CCS’s “Seven Steps to Health” with Dan and Julie Steinke, parents of Danny who survived childhood leukemia. Dan Steinke is especially candid when asked his opinion: “What did they just describe to you? Lifestyle,” he says. “The blame games. Your fault. No matter what happened, it’s all your fault that disease. What you did.” Julie grimaces, barely containing anger at the suggestion that “lifestyle factors” could have played a role in their then seven year old son’s cancer causation. Instead, she describes the cause of Danny’s cancer as “environmental.” Dan reports that behind closed doors many doctors will say they believe 80 to 90 percent of cancers are due to environmental carcinogens, not genetics. The camera zooms in on an industrial flare stack and text flashes across the screen with startling statistics: “About 14 million kilograms of carcinogens are released into Canadian air, land, and water every year.” Now a teenager, Danny has two new tumours in his brain suspected to be caused by the radiation treatments he received as a child with leukemia. If lifestyle factors are the most common explanation of cancer causation—and where the CCS places its prevention focus—childhood cancers disrupt this hypothesis. Children do not smoke or work with hazardous materials; they exercise, are slathered with sunscreen and are told to eat fruits and vegetables.

When Mesley interviews American pathologist Samuel Epstein, a professor at the University of Chicago, he describes the CCS’s “Seven Steps to Health” as “this is precisely Doll and Peto. If you get cancer it is your own fault!” The 1981 Doll and Peto report stated
that thirty-five percent of cancers are diet related; thirty percent are caused by tobacco; and two to five percent are linked to environmental factors. This report has since been used as evidence to “prove” that environmental carcinogens are not a major cancer causation concern. Conversely, Epstein explains that he and other leading epidemiologists and scientists reviewed the report and found it “flawed in so many ways.” If the research was flawed from the start, and the report, at base, inaccurate, why is the Canadian Cancer Society relying on this thirty-year-old report to inform their cancer prevention strategy, Mesley wonders. The CCS currently spends about 10 percent of their annual budget on cancer prevention and the bulk of the budget is spent on healthy diet and anti-smoking campaigns, while Epstein maintains that Canadians are literally surrounded by carcinogens every day. *Chasing the Cancer Answer* exposes a few of the prime suspects such as birth control pills and growth hormones in conventionally raised beef. In 2005, the World Health Organization warned that “the pill” is carcinogenic and slightly increases the risk of cervical, liver, and breast cancer. The European Union banned the import of Canadian beef because one of the injected growth hormones is carcinogenic. When Mesley interviews environmental activists she learns that household cleaning supplies, garden pesticides, and personal care products sold in Canada all may contain carcinogens. In Canada, companies were not required to list all the ingredients of their products until November 2006. Currently, there is no law which requires industry to remove carcinogens from their formulations.

When Mesley interviews Mae Burrows, executive director of the Canadian Labour Environmental Alliance Society, she reports that in Canada “chemicals are innocent until proven guilty,” adding “and that is just not the right way to do things with the cancer rates the way they are today.” Canada, Burrows argues, needs to enact “The Precautionary
Principle,” where if a chemical is suspected of harm to human health, at any dose, it is
disallowed for human exposure. Diana Ward, filmed walking the streets of London, in the
United Kingdom giving out her cancer pamphlet *An Environmental Disease: The Case for
Primary Prevention*, says: “We are the experimental bodies.” Despite evidence from research
quarters which implicates specific chemicals in cancer causation, due to lack of long-term
controlled human studies, scientific proof remains elusive. Ward decries the inaction of
industry and government and terms cancer diagnosis and treatment as “big business:” “So I
call it the Cancer Industry. I make no bones about it. Cancer is a massive industry.”

Mesley reveals throughout the documentary that a big part of the cancer industry
narrative involves money—an enormous amount of money. When Mesley travels to Paris,
France, to the world’s largest pharmaceutical conference, she begins by asking drug company
representatives what they are doing to fight cancer. Then she boldly asks: “How’s business?”
“Great,” they all answer, smiling. *Chasing the Cancer Answer* states that in 2006 cancer
medications were the fastest growing class of drugs in the world, with sales exceeding 37
billion dollars. Not surprisingly, cancer treatments cost the Canadian government over 14
billion dollars each year. Mesley’s own cancer treatments cost the Canadian health care
system over 60,000 dollars. When Mesley asks Dr. James Holland, founder of the Paris
conference, why no drug companies are devoted to cancer prevention, he answers with
surprising candour: “because there is no incentive economically for them.” This is another
way of saying that the money, so to speak, is in cancer treatment, not prevention. Dr. Epstein
argues that the pharmaceutical company’s interest “is on returning the maximum profits for
their investors. As such, the more drugs are bought, the higher the profit. Now the more
disease there is the greater the profit.” Therefore, as long as cancer rates continue to rise there
is much money to be made because cancer is big business. However, Dan Steinke wonders why more cannot be done to prevent cancer and improve Canada’s bottom line. He says, “I gotta believe out of the billions of dollars we’re throwing at pharmaceutical research that we can throw some of that at environmental clean up and prevent a lot of cancers.” Mesley agrees, and asks “Why don’t we start dealing with the root problem and stop focusing entirely, or almost entirely, on damage control?”

Margaret Wente (2006), a columnist for The Globe and Mail newspaper, describes Chasing the Cancer Answer as a deeply flawed piece of journalism riddled with questionable science. She says: “Wendy Mesley’s well-meaning documentary has done cancer research a huge disservice. Advocacy journalism is all very well. But Chasing the Cancer Answer omits (or misstates) a number of important facts” (p. A17). Wente then attempts to convince the public that cancer is not an epidemic today but actually a degenerative disease. Moreover, she argues, most scientists believe only a fraction of cancers are caused by environmental chemicals, because dose is crucial in making chemicals carcinogens. Wente retreads the same terrain as Chasing the Cancer Answer, but rhetorically argues from the opposite standpoint. Moreover, Wente attempts to illustrate that the environment is a non-issue where cancer causation is concerned.

Also troubling is Wente’s (2006) suggestion that Mesley’s motivation for the documentary is “personal,” rather than motivated by a sense of what is in the public good and governed by journalistic integrity. Wente argues that Mesley “starred” in Chasing the Cancer Answer and “begins her piece on a personal note” (p. A17). She adds: “There’s every reason to admire Ms. Mesley personally. But her journalism, in this case, is another matter” (p. A17). While Wente attempts to malign Chasing the Cancer Answer because it reveals some
of Mesley’s breast cancer experience, I would argue that it is what Mesley comes to represent and perform, not simply the content of the documentary, which provokes Wente’s ire. In telling an unconventionally unhappy narrative of cancer, Mesley not only reports the bad news, she also becomes the harbinger and embodiment of it. Segal (2007a) terms *Chasing the Cancer Answer* a “renegade” cancer narrative: “What is interesting about Mesley’s report is not only what it argued but…how it was received” (p. 14). In regard to Wente’s criticisms, Segal argues that Mesley simply had “the wrong kind of story to tell” (p. 15). Mesley, she argues, is “the scene on which an ambient cancer played itself out” (p. 15). The argument of *Chasing the Cancer Answer* and Mesley’s personal breast cancer story become one in the same as they are effectively conflated in Wente’s public critique. As Segal asserts, 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 do not know about the causes of cancer” (p. 14). “It was not a personal narrative,” (p. 14) Segal concludes.

The concerns and problematics, the questions raised in *Chasing the Cancer Answer*, become elements of Mesley’s personal breast cancer narrative. The documentary is narrated by Mesley, and in giving voice to it she also becomes its embodiment, the scene on which what we know and do not know about cancer causation is explored. This performance is—without a doubt—integral to the affective power of the documentary. In heralding bad news, Mesley is—as Ahmed (2010) describes feminists who dare to disrupt the pursuit of happiness—a “killjoy.” Ahmed describes feminist killjoys as having much in common with female troublemakers. “Both figures,” Ahmed says, “are intelligible if they are read through the lens of the history of happiness” (p. 65). “Feminists might kill joy simply by not finding objects that promise happiness to be quite so promising” (p. 65). The cancer killjoy, then—
kin to the feminist killjoy and the female troublemaker, and I would add, the muckraker—
does not find happiness in the right places and refuses to remain silent. I would like to take
this conception of the cancer killjoy seriously, as the killjoy effectively performs an
intervention in mainstream cancer culture.

As Mesley reveals, she is a citizen with cancer but, importantly, a citizen with cancer
and a microphone. As a journalist, she is able to ask difficult questions of those in power, and
to ask such questions is to intrinsically make others uncomfortable. Hard-hitting questions
have the potential to scratch the veneer of all that is good and pleasant within breast cancer
culture. Ahmed (2010) argues that “the female troublemaker might be trouble because she
gets in the way of the happiness of others” (p. 60). Certainly, asking tough questions can
disrupt the happiness of others and often it is an act not without reprisal. “Happiness,”
Ahmed argues, “might be what keeps you out of trouble only by evoking the unhappiness of
getting into trouble” (p. 60). Here, Ahmed connects the female troublemaker and the act of
speaking out in response to injustice. “We can witness the relationship between
consciousness of injustice and being attributed as the cause of unhappiness” (p. 61).

Mesley—in an act of consciousness and a sense of injustice that one in two Canadians will be
diagnosed with cancer—unwittingly becomes the source of unhappiness for Wente by
reporting a bad news story. “There is a political struggle about how we attribute good and
bad feelings,” Ahmed says, “which hesitates around the apparently simple question of who
introduces what feelings to whom” (p. 69). Mesley evokes bad feelings, for Wente in
particular, by introducing a disruptive narrative of cancer causation. In Chasing the Cancer
Answer, Mesley suggests that since cancer may be linked to environmental carcinogens, the
Canadian Cancer Society’s prevention strategy of instructing individual management of
lifestyle factors may be wholly ineffectual. “Feelings,” Ahmed says, “can get stuck to certain bodies in the very way we describe spaces, situations, dramas” (p. 69). Mesley, in suggesting that cancer causation may have an environmental link—and that the Canadian public has every right to be concerned, even angry, about this lack of information—has anger stuck to her.

The interview Mesley (2006) conducts with CCS president Barbara Whylie deserves a close reading. Of this exchange Wente (2006) says: “Ms. Mesley performs a drive-by mugging of the Canadian Cancer Society. To be sure, they didn’t help themselves. Their CEO, Dr. Barbara Whylie, was embarrassingly unready for a hostile interview” (p. A17). Mesley does ask difficult questions and Whylie appears completely unable to answer them. However, that Wente interprets Mesley’s interview tactics as hostile—that she performs a “mugging”—speaks to how the cancer killjoy is read as misguidedly disrupting the peace. Interestingly, Mesley displays an immanently sunny demeanour throughout Chasing the Cancer Answer. In the interview with Whylie she smiles widely, even laughs out loud, while her questions go unanswered. “Anything but the sunniest countenance,” Marilyn Frye (1983) argues, “exposes us to being perceived as mean, bitter, angry or dangerous” (as cited in Ahmed, p. 66). The cancer killjoy, in speaking out and daring to disrupt happiness, is also aware that displeasure must be performed in such a way as to appear to acquiesce to a normative cancer politics in order to most effectively perform an intervention.

With each successive question Whylie becomes more uncomfortable, evidently unprepared and obviously unrehearsed, in defending the CCS’s cancer prevention strategy. Here, the cancer killjoy demands to know why our national cancer agency does not have an official position on carcinogenic products allowed for sale on Canadian store shelves.
Because the killjoy speaks out, she dares to suggest that behind a veneer of happiness something troubling might be concealed. While Mesley does not display open hostility towards Barb Whylie she does ask, pointedly and repeatedly, why the CCS does not do more to inform the public of potential environmental carcinogens. Whylie admits that “people should not be exposed to known cancer risk factors, probable risk factors, unknowingly.” Mesley injects, “But we are now.” Whylie concedes that this is probably the case. She maintains that the CCS does not know enough about environmental carcinogens, because there is no conclusive scientific research at this time. Mesley asks, “So what are we doing to fix that?” Whylie has no idea. When Mesley suggests that suspicious products be taken off Canadian shelves, or at the very least labelled with warnings, Whylie responds that this is the responsibility of government. When Mesley asks why “Magic Eraser,” a cleaning product marketed to families with children, contains formaldehyde, a known human carcinogen, Whylie protests: “I can’t answer the ‘why’ questions, Wendy.” If not the CCS, “Who else can we count on?” Mesley asks. Whylie responds: “We understand absolutely one hundred percent that it’s not good enough, it’s patronizing, condescending, and it’s not going to get the job done just asking people to live better.” Nevertheless, this is exactly what the CCS is asking the Canadian public to do in order to prevent cancer.

Like Mesley (2006), Segal (2007a) urges that different questions should be asked of breast cancer statistics and how cancer prevention is framed:

Why are more people diagnosed with cancer every year—both cancer of the breast and other cancers? What are the relations among carcinogen-producing industries, the pharmaceutical industry, the cosmetic industry, and the network of cancer support
groups? What does “prevention” mean on a national or global, rather than personal scale? (p. 16)

It remains important to query how cancer prevention discourse is engaged with when framed as a collective issue not simply an individual one. Laura Potts (2004) argues that dominant discourses of breast cancer risk—and cancer risk more generally—can be understood as essentially individualistic, emphasizing personal life history, genetic predisposition, and other lifestyle factors. “Thus,” she says, “preventative discourses of ‘risk management’ are framed as being dependent on individual strategies that urge compliance with authoritative advice to minimize these presumed risk factors, in terms of both ‘lifestyle’ and diet, and in terms of chemo-prevention” (pp. 133-134) or chemoprophylaxis, a drug-based approach to cancer prevention. In addition, programs designed to reduce risk are primarily concerned with early detection and seek to create better screening programs, rather than focus on the primary prevention of the disease. In contrast, Potts asserts that the environmental breast cancer movement—as an activist imperative—works to create an alternate collective narrative of cancer prevention, especially in calling for the Precautionary Principle, an ecologically based approach to public health.

Potts (2004) argues that the environmental breast cancer movement is formed around an ethical and political responsibility to protect public health, and that this impetus requires a reconceptualization of cancer risk. This shift:

involves a challenge to commonly held expertise (within medicine, toxicology, and the chemical industries), asserting the legitimacy of ‘lay’ knowledge claims, and giving rise to a ‘citizen expertise’ in relation to breast cancer risk that demands changes to the relations between state and populations at risk. (p. 134)
The environmental breast cancer movement turns to the collective dimensions of the disease rather than focusing on individual bodies and risks, so that risk itself is “written on the political and environmental body that is public and shared” (p. 134). Because the environmental breast cancer movement is led by those who have been diagnosed and treated for cancer, their leadership within the movement highlights why personal stories of experiential knowledge must count (p. 136). Here, the activist work done by those who have undergone diagnosis and treatment for cancer can be understood to reconceptualise breast cancer as a political issue in the public sphere, as much as it is also a deeply personal issue, represented by individual bodies forever changed by the disease.

In framing breast cancer risk as a collective concern, the environmental breast cancer movement also works to make space for the views of alternative experts, understanding that their knowledge claims often challenge biomedical narratives of disease causation. As Potts (2004) argues, activist knowledge claims are most often embodied and quotidian; indeed, these ways of knowing work within a feminist epistemology where personal, subjective, partial and situated knowledges count, and may actually function to engender stronger science. Potts argues that citizen experts seek to transform the way science is understood in the public realm and that they provide a transformational vision of the social, political, physical and economic environments that are implicated in, and may contribute to, breast cancer (p. 143). Conversely, a rhetoric that increasingly promotes individual responsibility, less reliance on the state and the shrinking of the public sector is not likely to be inclined to shift health or environmental policy agendas towards more regulation—of either endocrine-disrupting chemicals or financial markets. The neo-liberalism of
globally powerful northern states tends to militate against genuine shifts of power within governance; in this sense, the meeting rooms may be redecorated but remain essentially the same old spaces. (Potts, pp. 142-143)

*Chasing the Cancer Answer* argues that in order to do better—and by extension for all to have the opportunity to live better—more must be done at a systemic, collective level to prevent cancer. *Chasing the Cancer Answer* validates activist and citizen knowledge claims, advocating that members of the environmental breast cancer movement must be brought to the table so that the meeting rooms are not simply redecorated with a “business as usual” approach very much in place, but that new spaces for discussion can be created. Because, as Mesley says, “The missing part of the puzzle for me is that we are not doing enough about prevention.” “And I think,” she adds, “if some really smart and powerful people sat down together there could be decisions made that would be feasible and reasonable.”

### 5.3 Discourses of Personal Responsibility

In “Politicizing Patienthood: Ideas, Experience, Affect” Lisa Diedrich (2007) references Lisa Duggan’s (2003) assertion that two key concepts are associated with the neoliberalization of economic and cultural policies: privatization and personal responsibility. Diedrich asserts that in a political and cultural climate increasingly neoliberal in its objectives, a discourse of “patient politicization” has effectively been eclipsed by one of “personal responsibility”:

“The discourses and practices of the politicization of health, which seek to democratize expert knowledge and oppose personal responses to structural problems, have been covered over by neoliberal discourses and practices of personal responsibility” (Diedrich, 2007, p. 52). Mainstream breast cancer culture’s emphasis on the learning of individual risk factors,
knowing one’s genetic predisposition, and early detection via regular mammograms, can be framed to promote personal responsibility. “The focus,” Diedrich argues, “is on what the individual can and should do to determine her own risks for cancer, and her vigilance in monitoring her body so that she might detect her cancer early enough to be successfully treated” (p. 52). Of course, as Diedrich reminds us, what remains missing from such an approach is a “structural analysis that is concerned first and foremost with prevention of the disease in the first place” (p. 52). Furthermore, Duggan argues, neoliberal policy “promotes the privatization of the costs of social reproduction, along with the care of human dependency needs, through personal responsibility exercised in the family and in civil society—thus shifting the costs from state agencies to individuals and households” (as cited in Diedrich p. 52). Jackie Stacey (1997) in Teratologies: A Cultural Study of Cancer, remarks upon the “hyperindividualism” of New Right or right wing political agendas of the 1980s and 1990s—agendas, one could argue, very much present today in neoliberalism—that reframed “the individual as the supreme authority; the individual as agent of his fate; the individual as culpable in the face of failure” (as cited in Diedrich, p. 49). These discourses of neoliberalism, personal responsibility, and hyperindividualism, undermine the political utility of 1970s feminist health activism which sought to place women at the centre of their own experience or “the patient as her own expert” (Diedrich, 2007, p. 49).

Diedrich (2007) takes the phrase the “discourse of personal responsibility” from Teratologies, where Stacey (1997) explores “rhetorics of the self” through writings of personal, political and theoretical registers. Here, Stacey employs “experience as a series of textual ‘rhetorics of the self’ that connect competing forms of knowledge” in order to query the formations of these different knowledges (p. 24). Diedrich explains that “one such
‘rhetorics of the self’ is the discourse of personal responsibility that comes out of the therapeutic culture that has in many instances replaced a political culture” (p. 49). In particular, Stacey focuses on what emerged in the 1980s as a positive embrace of alternative medicine to examples of what she terms the “self-health” movement. Stacey positions “self-health” as a key component in the discourse of personal responsibility, while also readily admitting that she tried several alternative medicine modalities during her own treatment for breast cancer. While self-health discourses can initially feel empowering, especially in contrast to alienating experiences within biomedicine (Diedrich, 2007), Stacey (1997) agrees with Rosalind Coward (1989) that they fail to critique in a politicized manner the existing practices within the healthcare system. In fact, Stacey argues that

these self-health discourses (like their Thatcherite counterparts) lose sight of any social, economic or environmental forces which affect health and offer instead an entirely individualistic world view which posits the patient and her/his willpower at the centre of a manipulable universe. (p. 221)

Susan Sered and Amy Agigian (2008) introduce the term “holistic sickening” to the sociological literature on illness narratives. Here, they draw on interviews conducted with forty-six complementary and alternative medicine (CAM) practitioners in the Boston area who treat breast cancer patients, and found that these practitioners redefine a cancer diagnosis to that of a lifetime journey towards wellness. Cancer is reconceptualised as a symptom of problems that exceed the diagnosis of cancer. For example, Sered and Agigian argue:

Practitioners’ discursive construction of breast cancer transforms it from a discrete physical disease of the breast to a much larger problem potentially involving all areas
of a woman’s life (and possibly her past lives). This reframing is what we call holistic sickening; that is, a discursive process through which a discrete corporeal diagnosis (cancer cells clustered in the breast) is widened into a broad assessment of trauma, misfortune, characteristic defects, stunted spirituality, bad food choices, gender trouble, and a degraded environment. (p. 627)

CAM practitioners predominately reframed cancer “as a personally meaningful event as well as an opportunity to learn, grow, and heal on a number of levels” (p. 627). To be sure, there are innumerable dimensions “the patient might not have known she needed healing” (p. 627), and the healing journey can appear personally daunting, even arduous. In reviewing the interviews with CAM practitioners Sered and Agigian noticed that

if the breast cancer patient had to resolve her issues with self-esteem, anger, nurturing, work-family balance, and her relationship with her mother, not to mention transforming her negative or toxic thoughts into positive energy, meditating, doing special exercises, overhauling her diet and rearranging her furniture while navigating a positive female gender role in a society in which gender roles are rapidly changing, she easily could die of old age before becoming well. (p. 628)

In this way “holistic sickening” necessary precedes “holistic healing” and also imbues it with meaning (p. 628). “The particular paradox of holistic healing,” Sered and Agigian argue, “is that the very holism of its etiological narratives means that corresponding narratives of efficacy tend to be vague and open-ended, leaving patients (perhaps) in a chronically holistically sickened state” (p. 628).

Here, Sered and Agigian (2008) argue that “etiologies” “are narrative endeavours in that they explain how and/or why illness has occurred” (p. 621). The notion of “moral
etiologies” includes many types of etiological narratives, which are “contested domains” (p. 621) not only between patient and practitioner but also between different types of medical practitioners. However, they found that the majority of CAM practitioners interviewed not only spoke at length, but in specific detail, as to what they perceived to be the cause or causes of breast cancer. The most commonly referenced etiological framework was that of unhealthy contemporary lifestyles (and by extension environments), and according to this narrative, these attacks upset energy balance, cause stress, and compromise immune systems. Stress and energy imbalances provoke or exacerbate psychological problems and negative thinking further harms the immune system, upsets one’s energy balance, and/or causes stress, all of which makes individuals more prone to ill health. (p. 621)

Although not all etiologies were expressed in such a sequential manner, “the etiological discourses typically encompassed some sort of understanding that there were root causes (such as environmental degradation, character flaws, spiritual unrest, etc.) that led to proximate causes (energy imbalances, immune system deficiencies) that manifest as breast cancer” (p. 621). Both CAM and conventional biomedicine place great emphasize on individual responsibility in the manifestation of illness, with much less attention paid to the complex social determinants of health that may have contributed to disease.

While Sered and Agigian (2008) found that the complex etiologies of CAM practitioners initially offered meaning in relation to a breast cancer diagnosis, they also suggested that women were responsible, to a certain extent, for their own cancer. A narrative thread running through many of these accounts was that “the breast cancer patient herself somehow—directly or indirectly, partially or in full, created her own cancer” (p. 627).
“Emphasis on the individual woman’s culpability for her own illness (and potential death) is not, of course, limited to CAM practitioners; conventional US medicine also touts individual responsibility—if not blame—for illness” (p. 627). Biomedicine and CAM exist in the same contemporary context, “tapping into the same collective illness narrative that draws heavily on western discourses about the perfectibility of the body” (p. 627). Cancer—which can be understood as the very opposite of bodily perfection—can also be understood to defy discourses which attest to the perfectibility of the body, even as individuals and practitioners engage in and draw from this discourse when discussing a cancer diagnosis.

Importantly then, Sered and Agigian (2008) assert that “by holistically extending the notion of good health to encompass spiritual, relational and emotional factors in addition to physical ones, CAM practitioners can be seen as extending medicalization even further than conventional practitioners do” (pp. 627-28). This further medicalization can be seen in examining an emphasis on food and food choices, as “most of our interviewees offered diverse and extensive food-based etiologies and treatment plans” (p. 628) to their patients with breast cancer. “While the biomedical discourse vis-à-vis breast cancer and food generally is limited to avoiding certain kinds of fats and attaining and maintaining a lean weight” (p. 628), in CAM discourse food can occupy a central focus. For example, “Among CAM practitioners, the expectation that women will modify and control their diets is nearly universal (this is also the case for practitioners whose primary modality is not nutrition focused)” (p. 628). By extension, the expectation that women will modify and control their diet can also be read in discourses of normative gender constructions of women in relation to food—discourses which exceed that of CAM and breast cancer. As Sered and Agigian
illustrate, “holistic sickening is presented as a highly gendered process” (p. 628). According to some practitioners,

breast cancer is on the rise because women are too feminine, for others because women are too masculine. Being too emotional and/or repressing one’s emotions, being too nurturing or not nurturing enough, working at a computer or wearing an underwire bra all may cause cancer. (Sered & Agigian, p. 628)

Here, gender—and especially femininity—is over determined as the cause of illness. At base then, the narrative power of both CAM and conventional medical practitioners lies in how compellingly they are able to answer questions of who is sick and why, when or if healing has occurred and why, and what it means to be sick or healed—or, if healing is even possible. (p. 628)

The question of how to truly understand illness or healing is a compelling one, as is the question of whether holistic healing is actually even possible and what that might looks like, especially where cancer is concerned.

5.4 Crazy Sexy Cancer

_Crazy Sexy Cancer_ (2006) is billed as an irreverent documentary that chronicles actress Kris Carr’s experience with cancer. Carr was in her early thirties when diagnosed with a rare form of vascular cancer, Epithelioid Hemangioendothelioma (EHE). Her liver and lungs are mottled with tumours and she is diagnosed with Stage IV cancer—devastating, because as Carr notes, “There is no Stage Five.” After contacting several doctors Carr discovers that there is no known cure, and that traditional treatments such as surgery, radiation, and chemotherapy are deemed unnecessary because the EHE is not behaving aggressively. Her
oncologist recommends waiting for cancer to make the first move, and she is prescribed bimonthly CAT scans to monitor potential tumour growth. If fact, aside from the flu-like symptoms that first brought her to the doctor’s office, Carr is asymptomatic. By chance, the cancerous tumours are found by ultrasound, and Carr is driven to try and find a cure for EHE even if none is conventionally available. Upon diagnosis she stops auditioning for acting roles, sells her apartment in New York City, and commits herself to full-time healing. As a result, *Crazy Sexy Cancer* documents Carr’s four-year search for a cure and ends in “finding a life,” as she describes it. I would like to examine how this unconventionally titled cancer narrative—with its “crazy” and “sexy” underpinnings—can be situated in relation to the cancer killjoy. I would like to query if this documentary changes the terrain of the politics of survivorship, and I wish to question the film’s affective economy. At the outset, I argue that Carr’s performance of patienthood can be read through an entirely conventional framework, upsetting little of mainstream breast cancer culture’s normative prescriptions. In other words, while *Crazy Sexy Cancer* gives lip service to the cancer killjoy’s disruptiveness, the patient does not perform the role of the cancer killjoy.

When Carr discovers there that is no existing cure for EHE, she resolves to live much better than before. In undertaking to transform her life she comes to understand her public persona very differently: “No, I’m not the funny Bud girl,” she says, “I’m the poster child for cancer.” Now, in understanding herself as cancer’s poster child, Carr questions her former lifestyle as a hard-partying actress and the face of Budweiser beer. She asks “How did I catch cancer?” Ever ironic, she wonders:

*Was it cocktails, second hand smoke or the occasional first hand smoke while having cocktails? Kinky sex? Birth control pills? How about double lattes? Fat free dinners?*
Power bar breakfasts? Adolescent kleptomaniac phase? Cheating on tests and boyfriends? Lying?...Blocked emotions? Anger? Sorrow? No way! I’ve done my couch time. So I had a good time. It’s no worse than my peers. What about Hitler? He didn’t have cancer! Where’s the justice?

This line of questioning, although humorous, places cancer causation squarely in the realm of lifestyle factors. It emphasizes diet and emotions, both of which the individual is told to assume personal responsibility for. In taking personal responsibility for her health, Carr endeavours to completely overhaul her lifestyle. She abandons her career as an actress, changes her diet, gets regular exercise, seeks to cultivate a spiritual life, and explores the world of complementary and alternative medicine.

Eventually, Carr becomes a student of macrobiotic cooking, where her teacher proclaims that food is not only the foundation of good health, it also affects our emotions: “If you drink a cup of coffee you feel one way. If you have a glass of beer you feel a different way. How about if you eat carrots? Cabbage?” She explains that most people have no idea what they are consuming each day or how it affects their health. “If your dream is to create cancer then you can do that. If your dream is to create health and happiness you can do that,” she says. Food, then, and specifically meals created according to macrobiotic principles, is a way of actualizing the dream of health and happiness. And so Carr faithfully cooks for several hours each day, carefully preparing each of her meals. She admits that as long as she was shopping and cooking, she “felt in control, happy even.” One of the most appealing aspects of Carr’s personal performance that she humorously illustrates how she maintains a positive attitude. As an actor, she is blessed with a sense of comic timing and is not afraid to
look charmingly silly in front of the camera. She hams it up while overhauling her life and eating endless servings of macrobiotically prepared brown rice.

Still striving to find a cure for EHE, and taking on the self-described role of “full-time healing junkie,” Carr next adopts an exclusively raw food diet. Carr travels to the Hippocrates Health Institute, where instead of eating brown rice she drinks wheat grass juice and eats plates of sprouted foods. As she attempts to make her whole system more alkaline, blood samples are taken and viewed under a microscope. “Finally,” Carr says, “a way to measure my progress.” Undeniably, Carr is on a quest to transform herself from the inside out, from the cellular to the way she mentally manages to live with cancer. While on a twenty-one day fast she reflects: “It’s all mental management. Whether you can do something or not is in your head.” At this point, Carr firmly believes she can find a cure for EHE and her blood is again viewed under the microscope. It seems that adopting a raw food, plant-based diet has improved the quality of her blood. For Carr, this is proof enough of dietary success and the healing power of food.

At the beginning of Crazy Sexy Cancer Carr appears tired and overwrought in relation to her recent cancer diagnosis. Nonetheless she is as beautiful, thin, and blonde at the beginning of the film as she is at its end. Cancer does not diminish Carr’s attractiveness; in fact, she looks perfectly healthy throughout the documentary. In fact, her attractiveness only increases as the film documents how she adopts exceptional nutrition, restorative exercise, meditation and rest. Because Carr does not receive the traditional cancer treatments of chemotherapy, radiation, and surgery she does not suffer from the typical maladies of nausea, hair loss, and pain. She looks positively radiant when revealing that Crazy Sexy Cancer’s cameraman is her new boyfriend and future husband. Here, footage from the happy couple’s
wedding provides an emotional capstone to Carr’s narrative of personal success despite a cancer diagnosis. But what does it mean to accept this documentary’s assertion that cancer provides an opportunity for positive self-transformation and that one’s life can improve in the wake of a cancer diagnosis? Here, to be sure, personal transformation comes from accepting greater responsibility for how to live with cancer, and by discovering how best to live with cancer. *Crazy Sexy Cancer* is thus yet another iteration of the familiar tale that something good can come out of an otherwise very bad life event.

Increasingly, Carr’s approach to living with cancer becomes oriented towards its psychology or, more accurately, its spirituality. When she meets counterculture icon Bhagavan Das they discuss what Carr’s cancer diagnosis means, existentially. Das says “Your confrontation with death is the key to your spiritual life.” Throughout *Crazy Sexy Cancer* Carr’s cancer diagnosis functions as a catalyst for change in her professional, private, and now spiritual life. Her approach to routine daily activities becomes increasingly spiritual. Yoga, in particular, becomes more than a physical workout. Carr’s teacher begins class by intoning: “We accept that our ailment is an assignment, is an occasion to go deeper into ourselves in order to heal our bodies, feelings and lives.” Carr seemingly accepts that her cancer diagnosis is such an assignment and such an occasion to retreat inwards. Thus, she says, “cancer wasn’t killing me; it was pushing me to live,” adding, “maybe my lesson was about patience and acceptance. If I could learn to make peace with my disease when it didn’t go away, I could do anything.” In accepting that she must live with cancer, Carr’s performance of patienthood can also be situated as a prescription for others on how to live with cancer. She says, “I’ll never say cancer is a gift because I would never give it to you. But cancer can be a catalyst, a teacher. We all have things about ourselves we wish we could
change. Sometimes you can, sometimes you can’t.” Carr cannot find a cure for EHE and *Crazy Sexy Cancer* is a documentary about learning to accept cancer. Essentially, it is a normative cancer narrative packaged and billed as a disruptive one and, at base, a “triumph narrative” (Conway, 2007).

Kathlyn Conway (2007) writes against the cultural story of triumph in *Illness and the Limits of Expression*, acknowledging that while the triumph narrative is nearly impossible to ignore—because even when it rings false it still has allure (p. 17)—it must be resisted because it is not an innocent illness narrative. She argues:

The triumph narrative not only attempts to explain a phenomenon that is unknown and frightening—namely, illness and dying—but also embodies a belief that is given uncritical acceptance in our culture—that one can, with sufficient effort, triumph over illness. (p. 20)

Perhaps what is most problematic about the triumph narrative is its uncritical acceptance that illness truly can be overcome with an exertion of individual effort; indeed, this is part of its popular appeal. The triumph narrative highlights the maintenance of optimism when facing adversity and fighting disease, which are qualities many would like to embody should they have the misfortune to fall ill (Conway, pp. 17-18). What makes the triumph narrative so difficult to ignore is that it has become such a prominent cultural myth. Here, in narrative form, illness is courageously battled, diseases are triumphed over and those diagnosed willingly share the triumphal lessons learned from adversity (p. 20).

Belief in the triumph narrative is maintained, Conway (2007) argues, because culturally we are unable to live with reminders of suffering and death (p. 18). Instead, by keeping suffering out of sight, and “by keeping the ill, elderly, and dying out of view, we
manage to keep the story of the damaged body, of physical weakness or limitation, out of earshot” (p. 18). Further, the ill and disabled are met with a “coercive insistence that they rise above their suffering, battle their disease, and believe that everything will be fine in the end” (p. 18). Such a coercive insistence has the potential to become particularly damaging when one is actually completely unable to rise above, overcome, or change the circumstances of one’s illness or disability. If, at present, those who can optimistically put a positive spin on illness are valorized; distressingly, “those who hurt, complain, or give up” are labelled “bad patients” (p. 18). “Good patients,” Conway stresses, are those who are “uncomplaining, strong, and brave” (p. 19). Such a dichotomy is manifest in a breast cancer culture where survivors are celebrated and those who gave as equally valiant fight but did not survive are seemingly ignored. Conway cautions that “by subscribing so insistently to the narrative of triumph, we participate in a hysterical denial, as if by chanting ‘triumph’ we can ward off mortality” (p. 18). This is a particularly dangerous message where cancer is concerned.

5.5 Fuck Cancer

Kris Carr’s personal story is so prominent in Crazy Sexy Cancer (2006) that it is easy to forget that the documentary also touches on the narratives of other young women with cancer. Erin Zammett works for Glamour magazine, where she writes a daily blog about living with the disease. Zammett has a deadly form of blood cancer, chronic myelogenous leukemia, which is controlled with daily medication. She would like to end treatment so that she and her husband can try and conceive but, most likely, leukemia would then return. Erin’s sister Melissa also has cancer. Melissa received her diagnosis while seven months pregnant with her first child. She had to undergo cancer treatment, fearful for her developing
baby's health. During the filming of *Crazy Sexy Cancer* she undergoes a second treatment for Hodgkin’s lymphoma. Oni Faidah Lamplsey, a playwright and poet, says that despite a breast cancer diagnosis and treatment she kept writing. Her autobiographically inspired play, *Tough Titty*, chronicles the concerns of a young black woman who tries to remain married, raise two children, and endure cancer treatments. In 2005, it premiered at the Williamstown Theatre Festival. (Lamplsey died in 2008.) Jackie Farry was on a world tour managing a rock band when she was diagnosed with multiple myeloma, a rare blood cancer. Farry, a former host of MTV’s “SuperRock,” speaks candidly about being a single woman facing cancer and lacking adequate financial and emotional support.

After cancer treatments ended, saddled with fatigue, “chemo brain,” and mounting financial pressures, Farry called on her many friends in the music industry for help. As a result, a series of “Fuck Cancer” benefit concerts and raffles were held in Farry’s honour. When Carr notices an advertisement for a “Fuck Cancer” benefit in New York City she arranges to attend and meet up with Farry backstage. By way of a personal introduction Farry says, “I went to college for an hour. I don’t know how to do anything but tour with rock bands and deal with lunatics.” “Fuck cancer,” she says, “is my approach to cancer.” Presumably, she is referring to both the fundraiser in her honour and her attitude towards cancer. Farry describes cancer as a “shitty situation” to be in. Conversely, buoyed by the energy of the concert, Carr reflects: “Watching fifteen thousand people toast cancer made me feel like the cool one. In this crowd it was hip to have cancer.” No, certainly not. That night, while cancer may have had marginally hipper associations with the likes of Chavez, Cat Power, and, of course Jackie Farry on stage, the crowd toasts, at Farry’s request, “Fuck Cancer.” But the point was, and is, that cancer sucks. Cancer, the cancer killjoy argues, is
something no one should have to experience. And it is the kind of shitty situation that no one should have to face alone. Despite this sentiment, Carr gleams quite the opposite message: that cancer can be cool. Paradoxically what, if anything, was cool that night was the speech act “fuck cancer,” as well as the sentiment behind it and the performances on stage in support of eradicating cancer.

Interestingly, each of these young women’s cancer narratives, which function as a manner of subplot to Carr’s own cancer experience, are not nearly as pat or positive as Carr’s own story. These narratives dispute the idea that something good can come out of the cancer experience. What’s more, several of them refuse to tow the breast cancer culture party line, which espouses positive thinking as a prime coping mechanism and healing method. Jackie Farry, in particular, performs the cancer killjoy easily. She says, “the fuck cancer attitude came on pretty early.” When Carr gives Melissa Zamett a toque with “Fuck Cancer” embroidered across the front, Melissa is thrilled. With two of three Zamett sisters diagnosed with cancer, positive thinking holds little promise for the family. Erin and Melissa, diagnosed within such a short period of each other, fear for their remaining sister’s good health. Even Carr has fleeting moments of trying to perform the cancer killjoy, despite the general positivity of her message. At one point she says: “I just feel so fucking angry today….I don’t think that it’s fair that I have to do this. But here I am and I have no other choice, and it’s really frustrating.” She adds “Yeah, I’ve got issues. I’ve got fucking issues. I’ve got twenty-four little tumours. Twenty-four little fucking issues.” Despite this flash of anger, Carr’s struggle to remain positive is downplayed throughout Crazy Sexy Cancer. The film, predictably, concludes on a completely positive note:
Four years later my cancer is completely stable and I’m proud to call myself a survivor. What started as my desperate search for remission became a story of friendship, love, and growing up. Life is messy and brilliant, gorgeous and staggering, crazy and sexy, just like cancer.

On the contrary, the cancer killjoy proclaims that cancer is none of these things. The cancer killjoy argues that the cancer experience is made up of unhappy, cheerless and angry stories, and these breast cancer narratives need to be publicly performed. Clearly, just as angry breast cancer narratives are politicized around the struggle against happiness, the cancer killjoy struggles against cheerfulness. The cancer killjoy argues that cancer is a distinctly negative disease and it should be viewed through the lens of negative affects, with the goal being collective prevention of the disease. The cancer killjoy is a performative figure, in as much as her performances are designed to disrupt an emotional culture of good cheer and positive thinking. Marilyn Frye (1983) reminds us that “It is often a requirement upon oppressed people that we smile and be cheerful. If we comply, we signify our docility and our acquiescence in our situation” (as cited in Ahmed, p. 66). But the cancer killjoy will not acquiesce to the normative emotional politics of the disease because, as Ahmed articulates, the history of the feminist killjoy, kin to the cancer killjoy, is one of making trouble.

Ahmed (2010) argues that “Feminist genealogies can be described as genealogies of women who not only do not place their hopes for happiness in the right things but who speak out about their unhappiness” (p. 60). Feminists then must be wilful—killjoys must be vocal in their unhappiness—as much as they must be ever ready to disrupt normative discourse. Feminist killjoys, like cancer killjoys, in refusing to buy into the promise of happiness, are deemed unable to laugh or find humour in the right things: “In the thick sociality of everyday
spaces, feminists are thus attributed as the origin of bad feeling, as the ones who ruin the atmosphere” (p. 65). “Feminists,” Ahmed argues, “don’t even have to say anything to be read as killing joy” (p. 65). Feminists are inherently deemed to depress good feeling before they even say a word. The cancer killjoy can perform in the same way. If Crazy Sexy Cancer (2007) embraces positive affects to tell a story of personal transformation, Chasing the Cancer Answer (2006) engages negative affects to urge for collective cancer prevention. Crazy Sexy Cancer is a portrait of an individual’s undertaking of personal transformation after a cancer diagnosis, not an investigation of the environmental links to cancer. It is an exploration of how one individual manages lifestyle factors, and it can be read as a prescription for others on how to best live with cancer. Unlike Crazy Sexy Cancer, Chasing the Cancer Answer does not end on a high note; in the end, what remains is anger.

Mesley, despite her good-natured likability, is angry. She transgresses the acceptable performance of breast cancer survivorship by insisting we must prevent cancer in the first place. In the film’s final moments she says: “One in two is wrong. The number of people getting cancer is wrong. Our failure to do better in fighting this disease is wrong. I think we need to be a little wiser about the world we are creating.” After the barrage of bleak facts and painful, angry statements throughout Chasing the Cancer Answer, this much is understatement. Mesley asks, “At what point do you stop looking for the easy answers, like eat your veggies, and tackle the more complicated issue of all the carcinogens we’re eating and breathing and drinking?” Diana Ward is angry because cancer treatments are big business: “I call it a juggernaut. It’s an enormous thing that’s rolling along.” She firmly believes that cancer is an environmental disease and that not enough is being done to research cancer prevention strategies. When it comes to cancer, she says, “there are only two
choices…to let it happen and accept all the horrors it brings and watch our children enter the world with no chance, or do something about it now.” Danny Steinke also believes there is not enough collective action to prevent cancer: “So okay we’ve got cancer and we all feel bad.” But that is not enough, he insists: “So come on, step up.” “Step up” he repeats. Mae Burrows, also insisting that more must be done to prevent cancer, says: “I think we have to get really angry that the profit motives seem to be outweighing the responsibility for looking after our children’s health. That’s what we’ve got to change.” Therefore, in Chapter Six, I will shift attention away from anger to explore the potential of performing elegiac politics. The performance of elegiac politics is situated in the material, embodied, and affective dimensions of performing illness and, especially, in relation to industrial capitalism and a for-profit medical system.
6 Performing Elegiac Politics: Queering Gender, Sexuality and Breast Cancer

6.1 White Glasses

When literary critic and queer theorist Eve Sedgwick (1993) was first diagnosed with breast cancer, her initial reaction was: “Shit, now I guess I really must be a woman” (p. 262). She understands that it is breast cancer—not her female body (with which she already had an ambivalent, complicated relationship)—that will come to define her as a woman. Indeed, Sedgwick’s personal essay, “White Glasses,” is an elegy for her friend Michael Lynch, who died of HIV/AIDS, as well as an exploration of her own multifarious identifications as feminist, queer, fat, gay, and a newly initiated sick person. With a pair of coveted white-framed glasses—just like Lynch’s, which she deemed “the coolest thing I had ever seen” (p. 252)—Sedgwick attempts to have her self-described gay male identity recognized. After all, she declares: “Dare I, after this half-decade call it with all a fat woman’s defiance, my identity?—as a gay man” (p. 256). But she soon learns that instead of a “flaming signifier” (p. 255) the pastel of white glasses on a white woman “sinks banally and invisibly into the camouflage of femininity” (p. 255). As Sedgwick claims, the colour white performs differently on a woman than it does on a man. Rather than the gay man she envisions herself to be performing, by wearing white glasses, Sedgwick is further inscribed into the constrictive femininity of white womanhood.

Thus, Sedgwick (1993) asks for a reconsideration of whiteness, pointing towards its association with an affective politics of mourning and loss:

A white woman wearing white: the ruly ordinariness of this sight makes invisible the corrosive aggression that white also is: as the blaze of mourning, the opacity of loss, the opacity loss installs within ourselves and our vision, the unreconciled and
irreconcilably incendiary energies streaming through that subtractive gap, that ragged scar of meaning, regard, address. (p. 255)

The ordinariness of Sedgwick wearing white glasses belies how this act has elegiac overtones, pointing to the fragility of both Lynch’s and her own health and wellness. Sedgwick’s attempt to perform gayness, even if illegible, serves to expose the faulty stability of identity categories, even as breast cancer attempts to inscribe her back into the seemingly unproblematic designation of “woman.” In fact, during chemotherapy Sedgwick declares: “I have never felt less stability in my gender, age, and racial identities,” adding, “nor, anxious and full of the shreds of dread, shame, and mourning as this process is, have I ever felt more of a mind to explore and exploit every possibility” (pp. 263-64). That Sedgwick speaks to the categorical instability of sexuality, gender, age and race, as well as the affective dimensions of dread, shame and mourning vis-à-vis breast cancer, is of particular importance to this chapter, as is her intention to explore and exploit every possibility her breast cancer experience unwittingly provokes. I open with Sedgwick’s evocative description of how gender is inscribed through a diagnosis of breast cancer—rather than the other way around—to remind us how prevalent normative assumptions of gender and sexuality, not to mention class and race, are in breast cancer culture, as well as to note Sedgwick’s resistance to categorical understandings of performing identity. In this chapter I will explore the possibilities and problematics of queering breast cancer via Catherine Lord’s book-length work *The Summer of Her Baldness* (2004) and the lesbian television drama *The L Word* (2006), guided by S. Lochlann Jain’s (2007a, 2007b) conception of “elegiac politics.” At the outset, I will read what is understood as an autobiographical text, albeit one that challenges conventional autobiography, alongside a fictionalized representation of breast cancer. While
such a move may be understood as problematic, I hope it will provide an opportunity to further illuminate the ways breast cancer narratives, as a subset of illness narratives, already employ fictive aspects in performing personal narrative. More broadly, an exploration of how breast cancer patienthood is performed in breast cancer culture—and within a subcultural queer realm—provides an opportunity to examine how these performances are situated in material, embodied, experiential, and affective politics.

6.2 Performing Elegiac Politics

Sedgwick (1993) recounts that it was from her friend Michael Lynch that she learned “so much about how to be sick—how to occupy most truthfully and powerfully, and at the same time constantly to question and deconstruct, the sick role, the identity of the ‘person living with life-threatening disease’” (p. 261). For this performance “had long been embodied in him, and performed, by him, in ways which many of us, sick and well, have had reason to keenly appreciate” (p. 261). Of her identification with Lynch—not only in terms of gayness but a shared lesbian affiliation—Sedgwick says: “If what is at work here is an identification that falls across gender, it falls no less across sexualities, across ‘perversions.’ And across the ontological crack between the living and the dead” (p. 257). “Living in prognosis” (Jain 2007b)—living with breast cancer or HIV/AIDS, in that gap between the living and the dead, also serves to connect Sedgwick and Lynch in tangible and meaningful ways. While Lynch brought his own unique zest to the performance of illness, Sedgwick urges that these performances should also be examined within the context of liberatory identity politics and, especially, AIDS activism. One of its great triumphs, she argues, was that someone living with AIDS was made visible as dealing with the particularities of this disease and, due to
systemic exclusion in a for-profit healthcare system, “equally as someone who is by that very fact defined as a victim of state violence” (p. 261).

In 1991 Sedgwick first delivered “White Glasses” as a speech, and said: “What needs to happen now…is the even more radical and shaming realization that under the present regime of systemic exclusion from health care…every experience of illness is…a subjection to state violence, and where possible to be resisted as that” (pp. 261-262). In this essay Sedgwick wants to point to the potential of making connections between various identifications with illness—breast cancer and HIV/AIDS to name just two—as well as to forge theoretical connections between neoliberalism, illness, queerness, and performing illness queerly in a neoliberal historical moment. S. Lochlann Jain (2007a) calls for “elegiac politics” or a “retrieval of affect and death and illness in the context of profit” (p. 506). “Rather than a call to action, an elegiac politics recognizes the basic human costs of U.S.-style capitalism” (p. 506). In “Cancer Butch,” an article that critiques both breast cancer’s normative cultural politics and a lack of effective cancer prevention strategies, Jain asserts that she is not calling for a war on cancer and its terrors “to the extent that anthropologists get to make such calls” (p. 506). Instead, “The activist desire,” she says, “is to proliferate the possible identities of illness,” to include that of dying (p. 506). Jain stresses that queer analysis of breast cancer can do more than make space for, or somehow make visible, queer subjectivities within dominant discourse. She believes it offers more than simply highlighting how, in the United States, lesbians still might be the most undertreated group in society (p. 506). Instead, as I have previously mentioned, Jain argues for queering breast cancer because it “provides a radical intervention into the ways in which gender is constituted and inhabited” and can do so “in relation to industrial capitalism and the
distribution of one of its modes of suffering” (p. 506). Jain insists on a return to honouring bodily knowledge, to an examination of embodiment while focusing on queer bodies, narratives, and cultures, to forge expanding categories of illness identities and performances of breast cancer.

Jain (2007a) speaks to Sedgwick’s conception of how gender is constituted by breast cancer when she considers how the “relentless hyper- and heterosexualisation of the disease results in something of a recursive process through which gender is produced and policed” (p. 506). Jain suggests that querying the construction of gender in relation to breast cancer may prove somewhat less daunting than insisting on a discussion of mortality in relation to the disease, which would necessarily entail engagement with the very real pain and suffering involved and the tens of thousands die. Many known carcinogens continue to spew into the environment, a while there is still no real “cure” for cancer (p. 506), but that does not mean that queering breast cancer is not a necessary theoretical and creative intervention. In her own disruptive breast cancer narrative Jain effectively creates a context where cancer can come out of the closet (p. 506), and does so in an emotional tenor that is not simply about comfort or anger, but about mourning, which allows for public consideration, acknowledging the “agency and material humanity of suffering and death” (p. 506). As she says:

The point is not simply to eradicate the shame that has for centuries accompanied the disease, but also to acknowledge the ugliness of the disease and of the suffering it causes and to let that suffering be okay, not because it is okay but because this is what we have. (p. 506)

While the shame, ugliness, and suffering of cancer are not acceptable—and cancer is not okay—Jain necessarily calls for a consideration of what this suffering means, especially
when it is what we have to contend with in the current historical moment. With this initial outline of elegiac politics in mind, and seeking the critical utility queer insight might provide in relation to breast cancer, I will first turn to Catherine Lord’s (2004) *The Summer of Her Baldness*; subsequently, I will come back to *The L Word* (2006) and reconsider it in relation to elegiac politics, cancer rage, and gender rage.

6.3 *The Summer of Her Baldness*

At the outset, I would like to suggest that in Lord’s (2004) *The Summer of Her Baldness* the performance of baldness can be read in relation to an activist imperative of performing illness, embedded in a conception of elegiac politics, as Sedgwick (1993) and Jain (2007a; 2007b) suggest. Baldness, it becomes clear, also functions to illustrate how gender and sexuality become unwittingly complicated by breast cancer diagnosis and treatment. Moreover, undertaking to examine the implications of embodying and performing baldness points to the violence that compulsory, normative conceptions of gender and sexuality impose on women and allied others, and, specifically, those diagnosed with breast cancer. When visual artist Catherine Lord loses her hair during chemotherapy she creates an online persona in response, “Her Baldness,” who sends out email missives to a select listserv. Her Baldness reports that chemotherapy is like “mainlining weed killer, which is what, to invoke the perversely feminized metaphor oncologists prefer, my particular ‘recipe’ sounds like. Adriamycin and Cytoxan: they fit right in on the pesticide shelf” (p. 48). When Lord’s breast cancer support group asks what her greatest fear is she answers, without hesitation, losing her hair. “Dying?” Her Baldness reports, “way down on the list, way below amputation, which is in turn way below my second fear, that when bald I will discover rolls of fat on the back of
my neck” (pp. 36-37). “There are none,” she adds in mock-relief (p. 37). Obviously, part of Her Baldness’s act is to employ sardonic humour.

Her Baldness also spends much time ruminating on what it means to be bald for a woman, in midlife and a lesbian with breast cancer. She is a larger than life character who speaks frankly of the horrors of breast cancer treatment, depression, shame, fear, loss of control, isolation and, notably, female baldness. But the narrative text remains purposefully fragmentary and imagistic: Lord includes not only the sent emails of Her Baldness but unsent emails, musings, photographs, and the email responses of friends and loved ones. The *Summer of Her Baldness* not only transgresses breast cancer’s normative cultural ethos by engaging with negative affects, but also blurs the lines between autobiography and fiction. Like the character Her Baldness, the book is a blend of the visual and textual, the personal and theoretical, and the online and offline aspects of communication and meaning-making in contemporary life. At base, Lord’s disruptive breast cancer narrative is an improvisation vividly illustrating how the diagnosis of breast cancer propels one woman into an unwilling, unplanned performance piece. In this performance, Her Baldness returns again and again to ponder breast cancer and embodiment and the transgressive aspects of female baldness.

When Her Baldness is newly bald and negotiating how to perform baldness in public she says, “I have not grown accustomed to my pate, but in an odd and tentative dance, we are becoming acquainted” (Lord, 2004, p. 40). “In order to walk down the street or into a restaurant or into a store,” she says, “I must both remember my pate and forget that I have it” (p. 40). Recently accessorised with a plethora of different head coverings and hats, Her Baldness comes to understand that the revealing of her bald head will be visible for an audience of only a privileged few. “I do not remove my hat in any of the doctor’s offices,
especially not the shrink’s,” (p. 37) she says. “It is a new relationship, we are not there” (p. 37). In truth, Her Baldness does not perform baldness loud and proud in the ways she had first hoped to. Instead, she remarks on what she perceives as her freakish visibility: “I feel like a freak...I have no style. I have no dignity. I’m marked. I’m a target” (p. 38). Her psychologist replies, carefully, that she does not look like any of those things; rather, she looks remarkably in control. Her Baldness replies: “It’s fake....It’s a performance. Don’t you get it? Can’t you see? Are you blind?” (p. 38). “The performance,” Her Baldness says, “will be thick enough to see me through. Collect the stares and use them later” (p. 40). When her psychologist then asks about focusing on baldness and how to best perform it, she admits “OF COURSE I’m displacing my anxiety about death…but I’m not dead. I’m bald. Bald is all that’s accessible” (p. 37). She explains: “When you face your worse fear you crack and when you wake up you find out you’re not dead, you’re bald” (p. 40).

Even if a fixation on baldness functions to displace a consideration of mortality, it is a visible mark of living with cancer and performs a strategic utility for Lord. Indeed it is Her Baldness who comes to realize she wants to be “marked by baldness as a woman with cancer undergoing chemo, as a woman confronting her mortality” (Lord, 2004, p. 44). “In fact, before I noticed that the decision had arrived in me I was already marked. Something knifed inside me, and I do not want to lose the external sign of that wound” (p. 44). Cancer is a wounding and baldness is a mark of that injury. As Jain (2007a) reminds us, “cancer injuries harbour ghosts: baldness recalls criminality and the holocaust as much as the subsequent performances (commonly read as codes of aggression) of punk rockers and lesbians” (p. 509). Baldness is not always read through breast cancer or even its many ghosts.
Her Baldness discovers this on a flight from New York to Los Angeles, when she hands her jacket to the flight attendant in business class and receives her first deferential “sir.” Lord (2004) notes, “Her Baldness has previously encountered gender misidentification” and “adopts the pedagogical strategy of nonconfrontation” (p. 117). Thus, Her Baldness prolongs her exchanges with the flight attendant whose name tag reads “BETH” and lingers over the available in-flight snacks and beverages.

She is so anxious to give the flight attendant an opportunity to reflect on gender possibilities that she asks for tomato juice in addition to club soda. The flight attendant is amicable, cooperative and patient. Her Baldness congratulates herself on her maturity in using details such as the temperature of a warmed cashew to give the flight attendant an opportunity to reconsider the social construction of gender without provocation or direct criticism. (p. 118)

Lord reflects that “perhaps, after all, cancer has been a transformative experience for Her Baldness” (p. 118). Yet Lord’s girlfriend, Kim, is becoming increasingly exasperated by the flight attendant. Rather than directly correcting her, she instead says loudly and repeatedly “Catherine,” whenever referring to her companion. Still, Beth does not make the connection. Here, Lord understands that Kim is “trying to shield Her Baldness from gender insult” (p. 122), but asks that Kim refrain from correcting Beth. For Her Baldness notes, “I WANT to be sir for five hours and twenty minutes. I’d rather be a bald white guy with bracelets than a sick white woman” (p. 122). Besides, Her Baldness decides she is actually flattered to be called “sir”, even that she has been “sir” since that first moment she handed over her leather jacket on Flight 19 (p. 119) and nothing will change the way her gender presentation is read.
“But,” she asks rhetorically, “isn’t Her Baldness a VERY smooth shaven guy? Or does the flight attendant think she’s a depilatory minded fag? Or an F2M?” (p. 119).

Her Baldness realises that her involuntary gender nonconformity via breast cancer, chemotherapy, and female baldness has found an uneasy and troubling solution: render the bald woman invisible. “If bald isn’t female, bald is fine. If bald isn’t female, bald isn’t grotesque” (p. 118). The whole problematic of breast cancer, female baldness, even the reality of her relationship with Kim, has found an uneasy solution when read as a man:

Out there among the clueless heteros, it’s easier to see a straight couple than a queer one. The luscious lipstick lesbian, blonde, good haircut, loaded with the signifiers of femme (an identity Kim emphatically rejects) is disappeared into straight woman. The skinny tortured pale butch (an identity to which I, on the other hand aspire), is disappeared into straight man. (p. 118)

Finally, Her Baldness questions what the flight attendant finds so confusing: “what is it that BETH can’t spell. L.E.S.B.I.A.N or C.H.E.M.O?” (p. 122) “Presumably,” she surmises, “the flight attendant would rather serve a guy who wears bracelets than Her Baldness” (p. 119), a woman undergoing treatment for breast cancer.

Early on in chemotherapy, Her Baldness decides against a wig and refuses to cover her bald head with what she considers a substitute, a fake and an incomplete replacement:

I have crossed it off my list the possibility of a substitute, a fling, a replacement, a temporary solution that would imply a temporary problem. Not even a red nylon Cher mane. No hirsute dildos for Miss Natural. Somewhere back there, right after the lesbian haircut, wig went out, wig landed in the garbage, wig no longer tweaked the
tender buttons, wig stayed on the store shelves. Wig looked wig, and cost plenty.

(Lord, 2004, p. 43)

As she recalls, when she first opted for a short haircut it gave temporary delight. Her Baldness reports, “it took me about five minutes to get with the program: outrageously mannish invert butchly LESBIAN haircut, the first one of my entire lesbian life” (p. 34). But when her short hair slowly but surely began to fall out, as chemotherapy treatments progressed, Her Baldness decides it is time for her head to be shaved. She reflects: “This is my life. It has changed irrevocably but it is the only life I have. I need to make it a normal life” (p. 37). Actually, in attempting to make her life normal Her Baldness refuses a wig and attempts to embrace, and truly perform, female baldness.

In the process, she discovers how hair, unlike any other signifier, is directly tied to both conceptions of health and wellbeing and to performing a certain kind of femininity:

Like color, which does not exist in isolation but is entirely determined by the adjacent colors, the neck, which lies between breasts and head, is entirely changed by the deletion of hair and the addition of pate. Minus accessories, pate pretty much fills the entire visual field. No accessories means minimal going on victim. On a woman of my age pate spells invalid. InValid. (Lord, 2004, p. 39)

Without accessories—and without hair—Her Baldness speculates that she is publicly read as an “invalid.” Here, “invalid” signifies being read both as unwell, as someone living with cancer, and also as not acceptable and not fully registering as a woman. Strangely, in acquiring a pate—in living with cancer and a shaved head—Her Baldness discovers that this performance requires another kind of maintenance, a meticulous kind of grooming not unlike that associated with high femininity. A pate is not as trouble-free as Her Baldness had hoped
it might be. It actually requires the kind of grooming she finds troublesome, inconvenient, not to mention somewhat distressing. Her Baldness, ever ironic, asks: “Is there something worse than cancer for a middle-aged dyke?” (p. 40). She adds, “Could I have male-pattern baldness? Is pateness—stubble-free and silky—something I will have to WORK to maintain for the next five or six months?” (p. 40). Here, in what could be read as a comment on performing masculinity—perhaps female masculinity—baldness comes to symbolise the performance of a different set of gendered expectations rather than a public release from performing “coherent” gender.

Baldness also provides an opportunity for Her Baldness to comment on queer gender and sexual politics. She explains that because of breast cancer “I’ve been reminded in an observation intended to be reassuring of the similarities between hats and dildos” (Lord, 2004, p. 41):

as Cathy Opie once said of the latter, I love to use them but I’m glad they’re removable. Personally, I know that Opie is not in actual fact the first person to float this boat, but now that the ship has sailed and she has left Los Angeles and gone to Yale to be a lesbian, as it were, it’s understandable that she would get the credit for some celebrated recent theorizing about gender performance. (p. 41)

In first taking a playful jab at celebrated queer photographer Catherine Opie, Her Baldness wants to bring theorizing about gender performance and queer sexuality to the subject of breast cancer. In a telling passage of rhetorical questions, she connects the centrality of hair to sexuality and gender performance but also to the notion of stable gender categories in relation to illness, specifically breast cancer. Her Baldness asks:
Q: Is hair as unnecessary a protrusion as a dick in most social circumstances?
Conversely, is hair as much fun as a dick in most social circumstances?
Q: If the penis is located between the legs, and the phallus is located between the ears, where is a lesbian’s hair when it is not on her head? (I have kept mine in zip-locked baggies, I confess, in anticipation of a future I do not yet understand, but this is a more literal answer than the sort I have in mind.)
Q: If a straight woman rushes to the wig store (get ready, get it in advance of the chemo, have it waiting so that it will be there when you need it…) what should a lesbian do? Wigs are tight. Wigs itch. Wigs are about passing. Or are wigs like lipstick? Get over it, apply the signifiers, hit the road.
Q: How come men OWN not only dicks but bald? In this year of the fabulous homeboy/dude/fag—take your pick of race and sexuality and combine as you will—how does a dyke lay claim to bald outside her own house? (p. 41)
Her Baldness closes by saying, “Only my lover has so far seen my pate” (p. 41). Despite Her Baldness’s cerebral and performative bravado, the idea of a public performance of baldness continues to be difficult, painful, and so far impossible.

In the context of breast cancer, female baldness can be read as a bodily performance situated within an elegiac politics. Her Baldness can be read to perform elegiac politics as she incorporates grief, loss, and fear into the act of mourning her lost hair. Baldness can be read as an injury, a wounding which makes the problematic of breast cancer, and those who suffer through its treatments, necessarily visible. It can also be read as a space of mourning as it connects cancer to the reality of suffering, and even death. Her Baldness illustrates that
cancer can wound in ways that feel impossible to articulate only in words; therefore, she inherently performs a manner of elegiac politics when she says:

Baldness is a scar. I want my scar….I don’t want to shop to cover my scar, which will at any rate fade and heal, just as the ones on my breast and under my right arm are doing. I do not want to pass. I do not want to go gently back into the world of people who are afraid of looking into the eyes of someone whose chances of dying in the near future are better than theirs by a long shot, or so they need to believe. Baldness becomes me, in a literal sort of way, a hell of a lot better than a pink ribbon. (Lord, 2004, p. 44)

Baldness, then, deviates from a normative breast cancer performance where as one of cancer’s many injuries, it is covered by a wig, an approximation of the hair lost to cancer. Her Baldness attempts to embrace a nonnormative gender performance and also to embrace a counternarrative to the one embedded in pink ribbon culture, where baldness is not a viable way to live as a woman with cancer. Importantly, Her Baldness does not provide a prescription for others on how to live with cancer; instead, her performance is an improvisation, a queer gesture towards making visible, and making space for, alternate possibilities of performing illness.

6.4 Living Elegiac Politics

S. Lochlann Jain (2007b) argues that “if the term ‘survivor’ offers a politics steeped in an identity formation around cancer, ‘living in prognosis’ offers an uneasy alternative, one that inhabits contradiction, confusion, and betrayal” (p. 90). Here, Jain highlights the necessity of
complicating identities formed around illness, breast cancer in particular, and reminds us how the politics of cancer survivorship are imbued with a disavowal of death and dying:

I don’t believe that cancer, or suffering more generally, can be understood cleanly through a politics that tries to disavow death (as the survivor politics does), or cheer it up (as the pink-ribbon rhetoric does), or deny or defer cancer suffering (as does the “drive for the cure”). (p. 89)

Instead, Jain asks for a consideration not only of the suffering cancer imparts but also the obfuscation of a cultural politics that strives to bright-side this very suffering, or even disavow this suffering, not to mention the reality of death and dying.

As an alternative to these established normative cultural performances of breast cancer survivorship, Jain (2007a) proposes a consideration of elegiac politics: “Instead of focusing on hope, cure, and the survivor figure, elegiac politics yearns to account for loss, grief, betrayal, and the connections between economic profits, disease, and death in a culture that is affronted by mortality” (p. 90). Elegiac politics requires a confrontation with mortality, and a serious consideration of how to make cultural space for death and dying. It also requires that negative affects of loss, grief, even betrayal, be given space in a context of breast cancer’s cultural politics that would rather disavow their existence. Negative affects can be understood as integral to elegiac politics, when the affective economy of elegiac politics pushes what might be considered private into the public sphere. Jain argues:

An elegiac politics argues for pushing the private face of cancer cultures—grief, anger, death, and loss into the public cultures of cancer—perhaps even if only alongside of LiveStrong, or sipping, driving, and walking for the cure—with the
recognition of the enormous economic profits and gains that parallel these losses. (p. 89)

Jain argues that read from a certain vantage point the entire cancer complex is about mourning, about absencing and presencing in ways that make it “hard and emotional and profitable” (p. 89). “The cancer complex both gives us the inevitable (we’ll die, why not of cancer?),” Jain says, “and holds the possibility of the counterfactual through the promises of early detection and cure” (p. 89). The staggering ubiquity of breast cancer belies that the disease need not be inevitable, even while its threat is disavowed through promises of “the cure.” Even when cancer is “cured,” women’s bodies are permanently altered through biomedical treatments, and the mourning, absencing and presencing of breasts, as symbolic and material, needs to be reconceptualised within breast cancer culture.

Samantha Crompvoets (2006) calls for a critical discourse to challenge the normative assumptions made of women with breast cancer and to engage instead with the complex relationships women have with their bodies and breasts during and after cancer treatments and surgery. She suggests that the near total absence of critical discourse which might reframe the post-mastectomy body in positive terms may impede a full recovery from breast cancer (p. 4). As I have previously mentioned, Crompvoets stresses that the way the post-surgical body is understood within breast cancer culture does not allow women to conceive of their own bodies as feminine, even whole, without a breast or breasts, because the mastectomized body is constructed as a problem that must be fixed (p. 4). Breast restoration via surgical reconstruction or prosthesis presents as the most viable option for women to be publicly understood as healthy and able to negotiate new understandings of body and self in life after cancer. For this reason, it remains vitally important to explore the particularities of
experiential knowledge, while also taking into account the particular ways in which one is
gendered and comes to embody this performance in the social world (Crompvoets, p. 19).
For, as Crompvoets poignantly articulates, “breast cancer and the post-surgical body are not
something we have and talk about, rather they are performed (p. 21). She argues:

The post surgical body is done in particular ways and is therefore not a singular entity
but multiple. Through a performative lens, the post-surgical body can be seen as
existing not as one, but many; as performed in a variety of ways. (p. 21)

Therefore, focusing critical attention on the post-surgical body provides another instance of
paying careful attention to how breast cancer knowledge is produced and how identities are
renegotiated during, and after, breast cancer diagnosis and treatment. Importantly, as
Crompvoets stresses, we are left to consider, critique, and explicate what remains unsaid
about the post-surgical body in the public discourse of breast cancer (p. 16). Because the
third season of The L Word (2006) insists on making explicit a connection between a
character undergoing diagnosis and treatment for breast cancer, and a character transitioning
from female to male, and of how both characters grapple with the concept of surgery, I will
turn to this fictional terrain now. Here, I question what this juxtaposition might say about
how gender and sexuality are formed, not only in relation to breast cancer, but in relation to
industrial capitalism, a for-profit medical system, and elegiac politics.

6.5 The L Word

Showtime’s cable television drama The L Word, produced by Ilene Chaiken, in Season Three
(2006) endeavours to engage the particularities of a breast cancer diagnosis in the lesbian
world of West Hollywood, Los Angeles. This storyline centres on professional tennis player
Dana Fairbanks and extends to Moira Sweeny, who begins transitioning from female to male while Dana undergoes treatment for breast cancer, and then rather quickly dies from complications. By positioning these characters in relation to each other, *The L Word* seems intent not only on attempting to queer breast cancer, but to reframe identifications and alliances around cancer. I would like to examine whether *The L Word*, in taking on such a controversial breast cancer narrative, is attempting to provide a manner of social commentary on the way gender and sexuality are constituted in relation to breast cancer, in the explicit terms used by Sedgwick (1993), Lord (2004) and Jain (2007a, 2007b). Or, if this storyline can be more comfortably situated within *The L Word*’s themes of uncomplicated lesbian community making, conspicuous consumption, and seemingly categorical understandings of lesbian subjectivities.

At first glance, *The L Word* undertakes to tell an unconventional breast cancer narrative by explicitly rejecting a hopeful, happy storyline—a triumph narrative (Conway 2007)—whereby breast cancer provides a vehicle for Dana’s progression towards greater spirituality, strength, and/or sexiness. The very fact that Dana’s youth and athletic prowess are not enough to conquer cancer, since she dies before the season even comes to a close, is at odds with a breast cancer cultural narrative of positive triumphalism. Interestingly, this clash of expectations does not play out in overt terms within the narrative, but revealed in the emotional interactions between, especially, Dana and Lara (as I explained in more detail at the end of Chapter Four.) Simply put, the fact that Dana dies from breast cancer, in the context of the often melodramatic world of *The L Word*, is certainly not enough to constitute this narrative as a disruptive one. What is disruptive is how Dana’s character in scripted when facing breast cancer, and how this storyline is performed in relation to Moira/Max’s
narrative. Read together, these two storylines form a breast cancer narrative that lends itself being discussed in disruptive terms.

The way gender is constituted in relation to breast cancer, and in particular in relation to a for-profit medical system and the suffering this invokes, situates The L Word well within a discussion of elegiac politics. In aiming to read The L Word in disruptive terms, it is not my goal to argue that the fictional world of The L Word is somehow liberatory, or even progressive, in its themes or characterizations. On the other hand, to read it as another example of a “gay show” constructed for a heterosexual viewing audience would function to ignore any queer cultural or affective world-making the show might also accomplish. Elegiac politics, the for-profit medical system, suffering and death in relation to both cancer and gender, are decidedly not happy topics, and not easy to engage with or sell/consume in the realm of popular television. In delving into this affective terrain it becomes apparent that further explorations of anger—even rage, to be sure—are needed. The L Word daringly wants to make a connection between breast cancer and transsexuality explicit, especially by focusing on mastectomy and top surgery, in a narrative performed through the bodies of Dana and Moira/Max. At first, this narrative seems forced, contrived, a poorly thought-out plotline and a problematic pairing of identifications around illness and embodiment. Indeed, this juxtaposition could be read as deeply problematic, and one could make the argument that The L Word problematically figures transsexuality as an “illness” that must be “cured” via biomedical means in much the same way as breast cancer is framed in this television drama. Despite this, there may be a more generative way to read this storyline and the explicitness with which these characters are brought into proximity with each other.
From the outset, Moira is portrayed as allied with Dana, somehow connected to her beyond the fact that she is a fan and watches all of her matches on TV. Conversely, when Moira is introduced to Jenny’s LA housemates, a lack of connection is immediately apparent. Shane and Carmen are puzzled by Moira’s butch and somewhat swaggeringly masculine gender presentation. In turn, it is readily apparent that Moira is uncomfortable in the company of Jenny’s lesbian friends. This becomes apparent when the group assembles at a high-end seafood restaurant to celebrate Jenny’s return from the Midwest. Here, the previously sensitive yet confident Moira withers in high-femme company. This scene highlights that her supposed gender nonconformity constructs her as an outsider, but the new-to-town and currently unemployed Moira is also an outsider socially and economically. Moira scans the menu, zeroing in on forty and fifty dollar entrees, and instead orders a salad and fries. When the food arrives, she appears distinctly uncomfortable with the highly stylized presentation of the entrees. Moira assures the group she enjoys lobster, and this is not why she has neglected to order it. Instead, seated at the head of the table, Moira asks if anyone knows why a lid does not have to be used when female lobsters are cooked in a pot. She explains that with male lobsters, as soon as they realise they are in boiling water and are being cooked alive, they begin to make ladders and bridges with their bodies in order to help each other out of the pot. But when female lobsters realise they are being cooked alive they begin to claw and drag each other further into the boiling water, towards death. Female lobsters would rather they all die than let even one escape the pot. “It’s a real shame, isn’t it?” Moira asks.

Clearly, this is not simply a curious story about male and female lobsters. It takes on metaphoric overtones when told by Moira, and it is obviously not the subtlest of parables. If
Moira sensed she was out of place and not entirely accepted by Jenny’s friends, as soon as she and Jenny are out of earshot the conversation switches to her gender presentation. Bette pronounces Moira a butch woman, a historical throw back, explaining to the others that where Moira comes from this is the only kind of visual language she has to express herself. Alice asks the others if they understand the language of those “shit-kicking boots” and “lumber jack walk.” Tina surmises that Jenny must have been really lonely back in Skokie, Illinois, because this is the only way she could have ended up with someone “so wrong” for her, wondering why she would want to “role play” with Moira. Carmen suggests that perhaps Moira is Jenny’s type, while Alice dismisses that idea that a “stone butch” could be anyone’s type. Shane questions whether “stone butch” is the best way to describe Moira, proclaiming labels irrelevant, especially butch and femme. Finally, Carmen denies that anyone could believe female lobsters are vindictive and aggressive while male lobsters are cooperative and helpful; Moira’s story must be wrong.

After the disastrous night out, Moira takes to the Hollywood Hills. An introduction to lesbian life in West Hollywood seems to have been both overwhelming and profoundly disappointing for Moira. Crouched beside her pickup truck set against the starlit night sky, Moira appears to be deep in thought, replaying what has transpired over dinner. Then she performs emotional distress, angrily slamming both hands against the side of her truck. She flings open the door forcefully, climbs into the cab and buries her face in her hands, sobbing. In this scene, Moira first displays the simultaneous and conflicting emotions of sorrow and fury typical of “Gender Terror, Gender Rage,” as discussed by trans theorist Kate Bornstein (1994):
We don’t deserve the ridicule, the stares, the fist in our bellies. We are entitled to our anger in response to this oppression: our anger is a message to ourselves that we need to get active and change something in order to survive (p. 81).

Bornstein adds: “I do believe that anger is healthy, that it can lead to a recognition of the need for action, but activism itself is best accomplished by level heads who can help steer others’ anger toward correct targets” (p. 83). A correct target for this anger is the gender system itself, Bornstein believes, yet vulnerable gender-nonconforming individuals are effectively unable to attack this system until they are somehow free of the need to participate in it (p. 83):

For a while, I thought that it would be fun to call what I do in life *gender terrorism*. Seemed right at first—I and so many folks like me were terrorizing the structure of gender itself. But I’ve come to see it a bit differently now—gender terrorists are not the drag queens, the butch dykes, the men on roller skates dressed as nuns. Gender terrorists are not the female to male transsexual who’s learning to look people in the eye while he walks down the street. (p. 72)

The “gender defenders,” Bornstein argues, are the actual “terrorists;” they are loaded with normative conceptions of what is “real” or “natural” and they publicly terrorize others via the very gender system that nonconforming individuals are forced to participate in (p. 72). Trans rage then, or the rage of any gender-nonconforming individual, as Bornstein suggests, is engendered by being subjugated by a gender system not of their own construction.

Overwhelmingly, the constraint, rage, and sorrow a binary gender system engenders is something Moira is altogether familiar with, as she negotiates life first as a masculine-identified woman, and then as a transgendered and/or transsexual man.
Billy Blakie, an outrageous club party promoter, invites Moira and Jenny to his home and they accept, not knowing what to expect. When they arrive, Billy asks if Moira goes by any other name. “No, not really,” she responds while Jenny volunteers that Moira sometimes goes by “Max.” Moira is then introduced to the other guests as Max. Billy’s friends appear to be gender benders of every stripe, and Moira is decidedly comfortable here. When Jenny is introduced as an aspiring fiction writer, Tom, another party guest, says that he writes non-fiction. Max asks what he writes about, and Tom says simply, “life,” adding that his narrative is about “a girl who becomes a boy, what he goes through, realising he’s really not a ‘she,’ girlfriends, family shit, T, top surgery.” “What’s top surgery?” Jenny asks. “A bi-lateral mastectomy,” Tom’s heavily tattooed girlfriend answers, “you know, similar to what a cancer patient would undergo except the nipples are reattached and the chest reconstructed with masculine contours.” Here, for the first time, The L Word brings breast cancer and trans identifications together in direct relation, initially only as a passing reference. “So it’s about your life?” Max asks Tom. “Or, maybe it’s about yours Max,” Billy says, adding, “if I’m presuming anything please tell me to shut up.” Much to Jenny’s surprise, Moira/Max reveals that she has thought about transitioning since childhood and has considered the possibility of becoming a man. When Jenny asks why Moira/Max has never mentioned it, Billy stresses “You have to talk about it Max.”

From this point onwards Moira recedes as Max emerges to greater prominence, but not without first experiencing negative reception in regards to the gender she presents. After again explaining to Jenny that s/he does not feel at all comfortable around Jenny’s friends or welcomed by them, s/he is coaxed into attending another party, this time with the promise of a two-piece suit to wear. When they arrive Dana is taken aback by Moira/Max’s gender
presentation, saying: “Look how handsome you look! You look good.” Despite this positive response to her masculine performance, Moira/Max is portrayed as the kind of gender-bender that makes others uncomfortable. When Moira lands a job interview, the male interviewer is clearly impressed with her technical skills, but asks how she got along with others at her last workplace. “No problems with you being hard to peg?” he asks. “Hard to peg?” Moira asks quizzically. “You’re neither fish nor fowl, Moira,” the interviewer says, adding “I’m not saying we’d discriminate because that’s one thing we would not do at intechmode. But we’re looking for someone who is a team player.” “Yeah, I’m a team player,” Moira says. “What side do you bat for Moira?” he asks laughing. “I’m kidding,” he says, “it was too good to resist.” Again, here, Moira is taunted, humiliated even, for performing female masculinity.

Overwhelmingly, being “hard to peg” and “neither fish nor fowl” creates an unliveable situation for Moira/Max. Certainly, Billy Blakie thinks Moira would be an attractive man, saying: “Max you’re the cutest boy I’ve ever seen.” He then asks if s/he is on hormones yet. Moreover, Billy offers to connect Moira/Max with black market testosterone, saying s/he doesn’t have to wait for a doctor’s prescription if s/he doesn’t want to. In fact, Moira/Max decides s/he will transition from female to male. This narrative is not told apart from the way gender is constituted in relation to industrial capitalism, but deeply imbricated in it. Moira/Max’s transition narrative—a transition that progresses at a rapid-fire pace—is inextricable from a neoliberal conception of agency that assumes an individual has the ability to purchase freedom. Instead of submitting to an assessment of gender dysphoria by entering the biomedical system, Moira/Max questions whether it is simply money that s/he needs in order to transform his/her life. Perhaps, if Moira had enough money she could simply become Max, rather than suffer through an inherently pathologizing understanding of
transsexuality via the biomedical model. That said, Moira/Max’s gender transition will always be at least partially dependant on conventional medicalization.

When Max consults a cosmetic surgeon to inquire about top surgery he is surprised to learn that his medical insurance will not cover the operation. Gender reassignment surgery is not an insurable benefit, as the insurance company interprets it to be an elective surgery. The surgeon explains that a subcutaneous bilateral mastectomy starts at $7500, and that other clients have raised the funds by staging “top surgery benefits.” Now, Max is going to have to make money, a lot of it, in order to afford this surgery and continue on the hormones he needs to make his life liveable. Finally, the two storylines—the transition narrative and the breast cancer narrative—are brought together when Dana, after recently undergoing mastectomy, is brought out for a night on the town. Shane and Carmen, having recently confronted Moira/Max when they found a used syringe in their shared bathroom, inform Alice that Moira/Max is on testosterone and is transitioning from female to male. “She’s having a sex change,” Shane says. “Yup,” Carmen says, “Moira is becoming a man.” “Are you guys fucking kidding me? For real?” Alice asks. She leans over and tells Dana, “Shane just told me Moira’s getting a sex change.” Dana, confused by what Alice has just said, says “What are you talking about?”

By way of an explanation, Alice reminds them of an article she wrote on gender reassignment surgery. Carmen interjects, exclaiming that she loved that article saying “It’s all about women who, like, become men, and they take hormones, testosterone, and they like cut off their hair, and they cut their tits…” she trails off mid-sentence, realizing her blunder, and that she may have offended Dana. Dana, visibly affected by what Carmen has just said, gets up saying, “I’m gonna go.” Dana, still recovering from surgery, attempts to protect her
vulnerable side as she pushes through the crowd, passing by Max without saying a word. If Moira has the power to change her gender and life and become Max, Dana is not depicted as having such power over her destiny. First she undergoes mastectomy, and then chemotherapy, and as her hair begins to fall out she says to Alice, “Look at me, I’m disappearing.” Here, she speaks to both her sense of self as healthy and well and, by extension, her sense of femininity, of female and lesbian embodiment.

In an attempt lift Dana’s spirits, heiress Helena Peabody books a private jet to fly the group to a basketball game. Max hesitates before joining them, saying that he realises what he is doing “is really freaking Dana out.” When Max is accidentally called Moira, Jenny announces dramatically: “Everybody, Moira is dead; long live Max.” Even if Max has not yet had the surgery he needs, he is still very much living as a man and has entered this new life in a meaningful way. On the jet, Dana and Max are seated directly across the aisle from each other, and when Dana hears Max refuse the offer of an espresso drink, explaining that he’s trying to stay as clean as possible, they strike up a conversation.

DANA: Is that ‘cause of the medication you are on?

MAX: Yeah, actually.

DANA: Me too.

MAX: I’m really sorry about what you’re going through.

DANA: Thanks.

MAX: I want you to know that I could understand why you wouldn’t want to be around me. I mean you worked really hard to create the body you have. And your whole life has been in that.

DANA: You’re right.
MAX: I want you to know, I mean you don’t have to accept this, maybe I shouldn’t even say it, but it’s life and death for me too.

DANA: But you don’t have cancer.

Here, Dana disrupts the idea that gender transition and breast cancer can be understood by the same terms. Nevertheless, Max endeavours to explain why his transitioning is a matter of life and death as well.

He recounts that the first time he tried to kill himself he was just ten, but he fought against it because his religious upbringing understood suicide as a sin. He explains that he even prayed to God to somehow put him in the right body. Dana is clearly surprised that Max’s gender has been the source of so much suffering, that he has been tormented by the feeling of living in the wrong body. When Dana and Max enter the basketball stadium together only to discover that Dana is being publicly honoured, a picture of her recent tournament victory flashing on the big screen and an expectation she will wave to the crowd, she turns to Max saying, “Get me out of here.” “Dana, it’s not for you” Max explains gesturing to Dana’s friends, “it’s for them.” Here he affirms that the entire outing can be understood to reassure Dana’s friends. It provides an opportunity for others to seemingly forget the suffering, pain, and change cancer has brought to Dana’s life, even if it provides no such relief for Dana. The extravagance of the whole trip, an event seemingly planned to allow Dana the opportunity to feel better—if not necessarily about her cancer—rubs Dana, and eventually Max, the wrong way.

When Jenny holds a top surgery benefit for Max, he is dismayed at how little money they raise. The morning after, Max informs Jenny they have raised exactly $3,452; Jenny is pleased to hear this. “It’s crap money,” Max exclaims, “it won’t even pay for one tit! Where
were all your rich friends last night?” “Where were all my rich friends?” Jenny repeats back incredulously. “Helena Peabody could pay for my entire transition in what she pisses away in like a day!” Max exclaims. Angrily, he swipes the money off the table, bills cascading to the floor. Increasingly, Max is portrayed as angry, unreasonably angry even. This aggressive gesture prompts Jenny to proclaim, “I don’t know you. You’re becoming a completely different person.” Max retorts “You don’t understand!” To be sure, Jenny misunderstands, or refuses to acknowledge, the source and complexity of Max’s anger, blaming it on his use of testosterone. Max is also rather inarticulate about his own anger and the source and depth of it. At several points, he too blames his rage on testosterone use, a legitimate yet underexplored aspect of the storyline. Jenny implores Max to consider, “when you get the body you need, who’s going to live inside of it? Is it going to be that sweet, kind, compassionate, gentle person I met,” she asks, “or is it going to be this mother fucking monster?!”

Problematically, Jenny does not understand Max’s anger as the manifestation of a complex kind of suffering. Max’s rage could be explored within the context of a restrictive, binary gender system—a deeply normative conception of gender performance—and one that may have brought him to the decision to transition. Now, he must find a way to pay for a legible gender, and body, while those who could help him financially do not see or understand the depth of his suffering. Read from this perspective, it would be possible to rearticulate his suffering as like other kinds of bodily suffering, specifically the type of suffering cancer can impart. Interestingly, throughout Season Three of *The L Word*, Max’s pre-operative body displaying changes via male hormones is articulated as “monstrous,” while Dana’s body clearly displaying the ravages of cancer is silently mourned. At Max’s top
surgery benefit, Dana compares scars with a shirtless trans man, reflecting that her breasts were once “really nice,” making explicit what she has lost. That Dana’s body has been amputated and chemically altered, is an open secret under the current iteration of breast cancer culture, but that does not allow her space to discuss freely what these changes mean or if they have affected her sense of gendered embodiment or sexuality. What becomes clear is that Dana is expected to function and perform as if she were the same as before, that she should refuse to acknowledge that cancer has permanently altered her body, her sense of embodiment, and that breast cancer is the source of much suffering, anger and rage.

6.6 Gender Rage, Cancer Rage

Susan Stryker (1996) addresses the intersections of monstrosity, transsexuality, and rage in her influential essay “My Words to Victor Frankenstein Above the Village of Chamounix: Performing Transgender Rage.” Stryker argues that in Mary Shelly’s novel, Frankenstein, or The Modern Prometheus, Frankenstein’s monster is able to resist, at least partially, the reductive category of monstrosity by learning human language:

Transsexual monstrosity, however, along with its affect, transgender rage, can never claim quite so secure a means of resistance because of the inability of language to represent the transgendered subject’s movement over time between stably gendered positions in a linguistic structure. Our situation effectively reverses the one encountered by Frankenstein’s monster. Unlike the monster, we often successfully cite the culture’s visual norms of gendered embodiment. This citation becomes a subversive when, through a provisional use of language, we verbally desire the unnaturalness of our claim to the subject positions we nevertheless occupy. (p. 200)
In particular, transgender rage, even if it does not provide a stable means of resistance, is both necessary and, as Stryker further articulates, inevitable, given that gender is necessarily performed in relation to dominant culture. Writing from the perspective of a trans person and scholar resisting normative gender and sexual politics, practices and performances, Stryker says:

Like the monster, the longer I live in these conditions, the more rage I harbour. Rage colors me as it presses in through the pores of my skin, soaking in until it becomes the blood that courses through my beating heart. It is a rage bred by necessity of existing in external circumstances that work against my survival. (p. 203)

Here, transgender rage is born of living in a social world that refuses to validate one’s existence, yet this rage not only becomes necessary for survival, it engenders the means with which to survive. For Stryker,

Transgender rage is a queer fury, an emotional response to conditions in which it becomes imperative to take up, for the sake of one’s own continued survival as a subject, a set of practices that precipitates one’s exclusion from a naturalized order of existence that seeks to maintain itself as the only possible basis for being a subject. (p. 209)

Throughout this essay, Stryker endeavours to articulate a transgender politic that speaks to personal and collective resistance to normative formations of gender and sexuality, but also one that engages critically with the affective dimension of resistance itself.

Here, “transgender rage,” as articulated by Stryker (1996), is reminiscent of both feminist theorizing of anger, disruptive breast cancer narratives, and the call of the cancer killjoy, as anger is positioned as the by-product of exclusion from power centres.
Significantly, it is a response to the normative constraints dominant culture depends upon for its continued regeneration. Stryker says, “the affect I seek to examine critically, what I’ve termed ‘transgender rage,’ emerges from the interstices of discursive practices at the collapse of generic categories” (p. 208). She explains:

The rage itself is generated by the subject’s situation in a field governed by the unstable but indissoluble relationship between language and materiality, a situation in which language organizes and brings into signification matter that simultaneously eludes definitive representation and demands its own perpetual rearticulation in symbolic terms. (p. 208)

The original rage becomes specifically transgender rage when a subject fails to properly embody and publicly satisfy gender norms. As such, Stryker argues,

transgender rage furnishes a means for disidentification with compulsory assigned subject positions. It makes the transition from one gendered subject position to another possible by using the impossibility of complete subjective foreclosure to organize an outside force as an inside drive, and vice versa. (p. 209)

Thus, it is through the process of performing rage that stigma is transformed and becomes the source of power with enormous transformative potential (Stryker, p. 209).

Transgender rage can be read in relation to cancer rage, and especially in a discussion of The L Word (2006), it should be discussed in such terms. Ultimately, perhaps, there is a terror embedded in both the cultural politics of breast cancer and a gender politics that espouses, and attempts to uphold, the gender binary. In both The Summer of Her Baldness (2004) and The L Word, cancer and normative conceptions of gender can be read as sites of intense suffering, suffering not unlike that an elegiac politics calls to attention as it attempts
to articulate the true cost of industrial capitalism. As sites of suffering then, gender norms and cancer both produce negative affects—anger, sadness, rage—which become not only symptoms of that suffering but sites of strange—and perhaps even transformative—power and empowerment. In such a negotiation of feelings, negative emotions become a kind of currency with which subjectivities attempt to perform agency and control, in an otherwise cheerful affective economy complete with a prescriptive politics of how to live. That cancer rage and transgender rage are brought together in *The L Word* is not insignificant. Like the solidarity forged between disparate ways of embodying and performing illness that Sedgwick (1993) illuminated in “White Glasses,” solidarity can also be formed through resisting and repairing dominant narratives, as I will explain more fully in my final chapter.
7 Counternarratives: Performing Resistance, Patienthood and Narrative Repair

7.1 Counternarratives

Barbara Ehrenreich’s personal essay, “Welcome to Cancerland” (2001), was one of the first explicit critiques of corporate-driven charity runs, walks, and bike races in the name of “the cure,” pink ribbon kitsch, and the relentless bright-siding of the breast cancer experience. She says in no uncertain terms:

‘Culture’ is too weak a word to describe all this. What has grown up around breast cancer in the last fifteen years more nearly resembles a cult—or, given that it numbers more than two million women, their families, and friends—perhaps we should say a full-fledged religion. (p. 50)

Like other recognizable religions, Ehrenreich argues, “breast cancer has its great epideictic events, its pilgrimages and mass gatherings where the faithful convene and draw strength from their numbers” (p. 50). The pink kitsch of teddy bears and pink-ribbon paraphernalia “serve as amulets and talismans, comforting the sufferer and providing visible evidence of faith” (p. 50). Ehrenreich continues:

Seen through pink-tinted lenses, the entire breast cancer enterprise—from grassroots support groups and websites to the corporate providers of therapies and sponsors of races—looks like a beautiful example of synergy at work: cult activities, paraphernalia, and testimonies encourage women to undergo the diagnostic procedures, and since a fraction of these diagnoses will be positive this means more members for the cult, both those that provide medical products and services and those that offer charitable sponsorships. (p. 51)
In framing breast cancer culture as a cult, or even a full-fledged religion, Ehrenreich explicitly troubles what has grown up around breast cancer. Whereas breast cancer was once hidden behind a shroud of secrecy and shame, today it is “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 strokes” (p. 45). “Now breast cancer has blossomed from wallflower to the most popular girl at the corporate charity prom” (p. 45).

Certainly, Ehrenreich’s critique is a rhetorically persuasive argument from a cultural critic who identifies that the cultural landscape of breast cancer is tainted with religious fervour, and nearly completely devoid of the feminist activism and ideology one might expect from a culture formed around such a women’s health issue. Ehrenreich’s critique is also positively informed by experiential knowledge because she too was diagnosed and treated for breast cancer, and then unwillingly initiated and thrust into the mainstream of breast cancer culture.

Ehrenreich (2001) argues that in the present moment, while we may believe we live in a time that has moved beyond patriarchal biomedicine, “obedience is the message behind the infantilizing theme in breast-cancer culture” (p. 52). Furthermore, women are “encouraged to regress to a little-girl state, to suspend critical judgement, and to accept whatever measures the doctors, as parent surrogates, choose to impose” (p. 52). Overwhelmingly, Ehrenreich is also troubled by personal narratives that support the paternalistic ideologies of mainstream breast cancer culture for she understands these narratives to feed the fervour of breast cancer culture. In particular, a certain type of personal narrative follows “the same general arc as the confessional autobiographies required of seventeenth century Puritans” (p. 50). In such narratives, Ehrenreich argues,
first there is crisis, often involving sudden apprehension of mortality (the diagnosis or, in the Puritan case, a stern word from on high); then comes a prolonged ordeal (the treatment or, in the religious case, internal struggle with the Devil); and finally, the blessed certainty of salvation, or its breast-cancer equivalent, survivorhood. (p. 50)

Ehrenreich is highly sceptical that these confessional narratives actually offer experiential knowledge of the disease, because this style of standardized storytelling also seems to be prescriptive, normative, and even coercive. Within the tightly knit world of breast cancer culture as pseudo religion, through the power of certain stories, “attitudes are subtly adjusted, doubters gently brought back to the fold,” (p. 50). Even when Ehrenreich was explicitly chastised for speaking out in ways understood to divert from the normally expected behaviours of a woman newly diagnosed and treated for breast cancer, she could not be swayed to join the ranks of mainstream breast cancer culture or the “cult of survivorship.” Indeed, she could not be pressured to write breast cancer’s standard story. For, as I have endeavoured to explore throughout this project, mainstream breast cancer culture has not only been resisted, and the ways in which breast cancer has been conventionally understood contested, it has been disrupted by counternarratives of breast cancer rooted in experiential knowledge. These personal narratives should be understood to do an important kind of emotional, political, and cultural work in the public discourse of the disease.

Often disruptive breast cancer narratives are initially performed in response to the very narratives entrenched in breast cancer culture, and through acts of narrative disruption they serve to create new testimonies, narratives, and knowledges about the breast cancer experience. In order to expressly situate breast cancer as a cultural formation, we might
employ the term “breast cancer culture” with the intention of retaining “the complex variety of meanings associated with the word culture” (King, 2006, p. xxii). Situating breast cancer as a culture also requires focusing on the dominant performances embedded within this culture as well as the high profile nature of its cultural signs, symbols, and style (p. xxiii). The mainstream of “pink ribbon” breast cancer culture has come to represent a hegemonic discourse of meanings and values, inextricable from a normative discourse related to femininity and white middle-class womanhood as well as to charity and breast cancer survivorship (p. xxii). A narrative like Ehrenreich’s “Welcome to Cancerland” (2001) can be understood as a counternarrative, since it undertakes to offer alternate perspectives on breast cancer in the public sphere; moreover, it also does a kind of cultural work as it dislodges the power of mainstream breast cancer culture and its dominant stories of the disease.

Counterstories, Nelson (2001) argues, are exactly the kind of tools needed to repair damage enacted through oppressive power systems, and in this instance mainstream breast cancer culture, with its prescriptive and didactic stories, can be understood as such an oppressive power structure.

In particular, the counterstory positions itself in relation to master narratives—“the stories found lying in our culture that serve as summaries of socially shared understandings” (Nelson, 2001, p. 6)—by refuting the master narrative and telling instead a different version of what heretofore might be understood as “socially shared understandings” (p. 6). For example, Ehrenreich (2001) tells a very different version of initiation into the world of breast cancer culture and life as a breast cancer patient than the master narrative known as “the standard story of breast cancer” (Segal, 2007a), with its insistence that not only will all turn out well in the end if one musters faith but that positive thinking, and submitting to an
infantilizing culture and patriarchal biomedicine is the surest way to a happy ending. As Nelson (2001) argues, master narratives are often “archetypal, consisting of stock plots and readily recognizable character types” (p. 6) and they are used not only to make sense of experience but to “justify what we do” (p. 6). Master narratives, “as the repositories of common norms…exercise a certain authority over our moral imaginations and play a role in informing our moral intuitions” (p. 6). Master narratives are not innocuous; in fact, they have a distinctly normative orientation when their ethical impetus is packaged as “commonsense knowledge” or billed as a narrative of commonly shared truths.

In contrast to master narratives, counterstories are narratives that “constitute a revised understanding of a person or a social group” (Nelson, 2001, p. 8). These stories are “developed for the express purpose for resisting and undermining an oppressive master narrative” (p. 8). By constructing a counterstory based on experiential knowledge and narrative elements that the standard story has chosen to undervalue (by underplaying them or ignoring their significance), through correction and augmentation “the master narrative is morally reoriented” (p.8). This allows the teller of a counterstory “to dissent from the interpretation and conclusion it invites” (p. 8). Counterstories identify an oppressive yet commonly held understanding, knowledge, or assumption manifest in the master narrative and attempt to change meanings in public discourse. Counterstories, then, as Nelson argues, are “narrative acts of insubordination” (p. 8). Ehrenreich’s “Welcome to Cancerland” (2001) is such an act of narrative insubordination in as much as it is also an exemplary counternarrative telling a very different story of the cancer experience, full of insights into how one might alternatively perform in breast cancer culture during diagnosis, in treatment, and in life after cancer. Ehrenreich suggests that the emotional performances and normative
identities culturally demanded of women with cancer demand feminist resistance and that the didactic imperatives found in the mainstream of breast cancer culture must be countered with necessary acts of reoriented ethics. Ehrenreich’s counterstory shows that the mainstream of breast cancer culture is actually embedded not only in normative narratives but in normative performances of breast cancer patienthood and survivorship. Undertaking to deconstruct these cultural performances, then, works in tandem with a project of narrative resistance whereby experiential narratives of breast cancer refuse to rehearse the standard story of breast cancer, as the teller also refuses to perform the master narrative of breast cancer in the quotidian realities of the day to day.

7.2 Performing Resistance

If what has formed around breast cancer can be termed “breast cancer culture,” as many persuasively argue (Ehrenreich 2001; King 2006; Klawiter 2008), then both normative and disruptive performances within this culture of a breast cancer diagnosis, treatment and survivorship are in need of explication. D. Soyini Madison and Judith Hamera (2006) describe “cultural performances” as “conventional forms of performances because they are framed by cultural conventions” (p. xvii). In this view, “self-conscious and symbolic acts are ‘presented’ and communicated with a circumscribed space” (p. xvii). Importantly, the descriptions of the self in action that appear in autobiographical texts—and in disruptive breast cancer narratives to be sure—most often refer to a prior embodied performance, as Kristin M. Langellier and Eric E. Paterson (2006) note in exploring the particulars of “personal narrative performance” (p. 154). These stories, in one way or another, tell a tale of “what happened to me.”
In the late 1960s sociolinguists William Labov’s and Joshua Waletzky’s work on “oral versions of personal experience” sparked interdisciplinary study of personal narratives, an endeavour that has since been taken up with renewed enthusiasm in the field of performance studies (Langellier & Paterson, 2006, p. 153-154) as well as autobiography studies. The performances of breast cancer culture and disruptive breast cancer narratives might be better understood by bringing them to a theoretical conversation with performances of the everyday. As Langellier and Paterson claim, the Labovian model “broke through to performance in everyday life along with all sorts of other self-presentational behaviours” (p. 154). What is known as the Labovian model “textualizes experience in referential clauses that presume a real event prior to narration” (Langellier & Paterson, 2006, p. 154). In reading autobiographical narratives of illness, of breast cancer in particular, and instances where the narrator describes the self in action, these acts can be read as performance, in the same way that performances of everyday life might be read on the screen, stage or street. Performance, however, is often referred to as a “contested concept,” and for valid reasons because “as a concept, method, event, and practice it is variously envisioned and employed” (Madison & Hamera, 2006, p. xi).

As D. Soyini Madison and Judith Hamera (2006) posit in “Performance Studies at the Intersections,” on multiple levels “performance ‘means’ and ‘does’ different things for and with different people” (p. xi). On one level performance is understood as theatrical practice, as drama, acting, performing, but performances need not be limited to or by this understanding. In recent years, “performance studies has undergone a small revolution” (p. xii). From a theoretical perspective, the field of performance studies has evolved into
exploring the various ways bodies make “culture, affect power, and reinvest their ways of being in the world” (p. xvii). Madison and Hamera argue:

The insistence on performance as a way of creation and being as opposed to the long held notion of performance as entertainment has brought forth a movement to seek and articulate the phenomenon of performance in its multiple manifestations and imaginings. (p. xii)

Autobiographical performances, personal performances of illness, illuminate the impetus of both creating and being where, necessarily, experience informs the performance as much as experience may also be engendered through the performance itself. Madison and Hamera argue that what we experience may be variously expressed as anecdote or gossip on one end of the performance spectrum, or may be manifest in novels or film at the other end of the spectrum (p. xvi), with various levels of performance in between. When “experience presses forward from the field of the day-to-day it becomes the incentive for expression” and “it is then no longer a personal reality but a shared one” (p. xvi). “In the evolution from experience to expression, we have simultaneously crossed the threshold of performance” (p. xvii), into performing in the cultural world. The movement from experience to expression is neither a neat nor static one, and as previously suggested experience may actually begin in performance rather than precede the performance. At base, “performance evokes experience, just as experience evokes performance” (p. xvii).

Notions of cultural performances are necessarily complicated by theoretical explications of “performativity;” as undoubtedly the power and potentiality of performativity continues to attract the attention of theorists across disciplinary study. Because performativity lends itself to interdisciplinary inquiry it has been deployed as a theoretical
concept in fields not limited to linguistics or performance studies, but literature and life writing studies, gender and sexuality studies, and queer theory. As performance theorist Amelia Jones (2000) stresses:

The performative has this capacity of eliciting charged engagements and so of politicizing our comprehension of bodies/selves (and of culture in general) because it specifically marks body/self as contingent on body/other and exposes the investments behind every attribution of meaning and/or identity. (p. 13)

Here, the performative not only has the potential to charge an engagement with bodies but also with culture, as it stresses how the body is contingent and charged with meaning. Also, cultural performances can be understood as performative through particular ways of reading, locating, and investing in these contingent performances. Further, as trans and gender theorist Susan Stryker (2006) argues,

To say that gender is a performative act is to say that it does not need a material referent to be meaningful, is directed at others in an attempt to communicate, is not subject to falsification or verification, and is accomplished by ‘doing’ something rather than ‘being’ something. (p. 10)

Stryker reminds us that, through a performative lens, a woman is someone who says she is one and then performs what “woman” means; therefore, the biological body is no guarantee of gender, as it functions instead as a vehicle for speech acts and gender performances (p. 10). Here, it is readily apparent that Judith Butler’s (1990) articulation of gender performativity as an iterative practice has been extremely influential in expanding notions of performativity. In brief, Butler’s notion of performativity as the repetition of stylized acts can be seen to extend Jacques Derrida’s notion of performativity as combining citationality and iterability, drawing
on J. L. Austin’s conception of performative speech acts. Nevertheless, it is Butler’s theorizing which has served, as Jayne Wark (2006) suggests, “to place the notion of ‘performativity’ literally at centre stage” (p. 176).

Yet, as Wark reminds, Butler (1990) necessarily distinguishes “performance” from “performativity” in Gender Trouble, suggesting that performance constitutes a “bounded act” (as cited in Wark, 2006, p. 176). However, as Wark also points out, performance theorists have necessarily critiqued Butler for this seeming oversimplification of performance. Performance, as it has been explored here, is not understood as a bounded act; instead; it has been deployed to expand notions of performance in cultures of illness and breast cancer world-making, in order to examine what these performances can do and how. Performativity must also be redeployed so that it might move beyond a conception of repeating theatrically stylized acts “into the more deeply relevant evocation of performativity as ‘nonessentialized constructions of identity’” (Madison & Hamera, 2006, p. xix). “It is in cultural performances where performativities are doubled with a difference: they are re-presented, re-located and re-materialized for the possibility of a substantial re-consideration and re-examination” (p. xix). Performativity, then, is deeply imbricated in the performances of the everyday, while it is also intensified in instances of wilful cultural performance (p. xix). Performance theorist Elin Diamond (1996) argues that

When performativity materializes as performance in the risky and dangerous negotiation between ‘a doing’ (a reiteration of norms) and a thing done (discursive conventions that frame our interpretations), between someone’s body and the conventions of embodiment, we have access to cultural meanings and critique. (as cited in Madison & Hamera, p. 5)
This kind of theoretical explication is very helpful to consider when undertaking to situate both the meaning-making and the critique inherent in the project of “performing resistance” within breast cancer culture, as performativity becomes cultural performance.

Phaedra C. Pezzullo (2003) highlights cultural performances in public life and acts of resistance to the mainstream of breast cancer culture by drawing from participant observation of the “Stop Cancer Where it Starts” tour organized by the Toxic Links Coalition of the San Francisco Bay Area. She understands the TLC, as organizer and enactor of the educational, noncommercial advocacy tour, to constitute a “counterpublic” that served to both challenge and invite public audiences to engage with them—and even to join them—in the disruptive performative instances of the “Stop Cancer Where it Starts” tour (p. 347). In analysis of the tour, Pezzullo stresses the “non-verbal activities that are involved in negotiating public life, including physical, visual, emotional, and aural dimensions” (p. 347). The tour adopts and adapts the rhetorical and performative strategies of an environmental justice “toxic tour,” whereby participants travel as witnesses to communities ravaged by industrial pollution; this “toxic tour,” instead, takes participants to the front doors of institutions the TLC believes responsible for allowing and contributing to environmental degradation involving potential carcinogens (p. 347).

Corporations, governmental agencies and non-profits have all been targets of critical engagement and featured stops on the “Stop Cancer Where it Starts” tour. Performed in response to National Breast Cancer Awareness Month, the Toxic Links tour publicly contests the designation of a single month, October, to be filled with events primarily designed to raise awareness of the disease and promote early detection efforts. Often these activities are unproblematically endorsed by those identifying as proud breast cancer survivors, who further
promote a culture of pink-ribbon fundraising campaigns and public service announcements.

NBCAM, endorsed as a legitimate and reasonable response to the issues that breast cancer poses, also constitutes a master narrative that dominates public discourse of the disease and, as Pezzullo notes, has generally done so with very little public opposition and has “become institutionalized as hegemonic ‘common sense’ in the current approach to breast cancer in the U.S.” (p. 346).

In opposing the rhetoric of NBCAM—even publicly questioning its corporate sponsorship and especially its early ties to companies of dubious ethics such as pharmaceutical and chemical giant AstraZeneca—the participant performers of TLC’s “Stop Cancer Where it Starts” also aimed to shift the discourse from early detection and screening to legitimating the possible environmental causes of the disease and thereby emphasizing the need to stop production of a number of potentially harmful toxicants and carcinogens. In fact, the TLC was successful in petitioning the cities of San Francisco and Berkeley and the County of Marin to resist the rhetoric of NBCAM and to rename October “Stop Cancer Where It Starts Month” (Pezzullo, 2003, p. 354). This instigated more than a simple discursive shift in language regarding how best to understand the root causes or causes of breast cancer. The Toxic Links tour sought to perform in a way that “attempted to interpellate people into an identification with the TLC” (p. 347), for the impact of this counternarrative and the strength of this counter public could be potentially bolstered with more allies added to the ranks. In her study of the San Francisco Bay Area, Maren Klawiter (2008) situates breast cancer culture as a “field of contention,” a site made up of three “cultures of action” each with a distinct relationship to the performance of “body politics.” The first culture of action, “early detection,” sought to normalize breast cancer and espoused the fit, feminine body with wig,
breast prostheses and reconstruction as emblematic of successful performances of patienthood and survivorship; the second, “patient empowerment,” boldly embraced body deviance, baldness and one-breasted realities without shame; the third, “cancer prevention” performed the grotesque deformities inflicted on bodies in communities victimized by toxic environments and pervasive carcinogens (p. 47).

In enacting a vivid instance of cultural performance by means of the tour, the TLC enlisted speakers, bold campaign messages, and costumed performers to convey its message, all of which served to emphasize its particular relationship to political performance and body politics. The “Stop Cancer Where it Starts Tour” of 2001 proceeded on foot from corporation to corporation, with a diverse group of speakers from coalition groups at each stop, and along the way stopped traffic and redirected bystanders on sidewalks (Pezzullo, 2003, p. 354). It generally attempted to interrupt any presumption that where cancer is concerned a “business as usual” motto is an environmentally and politically just stance. In addition to encouraging the use of eye-catching signage, with messages such as “HEALTH BEFORE CORPORATE WEALTH,” tour participants were asked to donate a dollar for a pin that read “fight the CANCER INDUSTRY” and subverted the iconic pink ribbon by turning it upside down and into a noose, suggesting that not only have breast cancer awareness campaigns gone awry but, controversially, they are actually complicit in the killing of women (p. 355). Costumed performers such as the Queen and King of Cancer, with deadly white faces and dark sunken eye makeup (p. 355), silently imparted a message through a body politics of the macabre. The tour “created an inventive, spontaneous, persuasive, and risky mobile theatre for cultural performance” (Pezzullo, 2003, p. 355).
In particular, one participant although not an official member of the Toxic Links Coalition, performed in the “Stop Cancer Where it Starts” tour through a body politics that illustrates the physical and emotional realities of cancer. RavenLight arrived in a black SUV in dramatic fashion just before the tour began, wearing a red dress, red hat and a black flower and accompanied by a woman wearing a gas mask. When the vehicle pulled to the curb, RavenLight exited and immediately walked to the front of the police line, as they attempted to allow free entry to corporate headquarters, unbuttoned her dress, and slipped her right arm out to explicitly expose a mastectomy scar to police, whereby she received a cheer from tour participants (Pezzullo, 2003, p. 356). As Pezzullo notes, the police were unable to arrest her for indecent exposure—according to California laws the public exposure of a woman’s breast is illegal (p. 356)—for she had exposed not a breast but its absence, in the form of a vivid scar further materializing the breast’s amputation. Although some walking passersby and drivers on the street appeared visibly struck, perhaps even disgusted, by RavenLight’s performance, others were obviously moved and. In particular some tour participants congratulated her for her bravery and honesty, in publicly showing her body in such a way (p. 356). As Pezzullo notes, “her body’s performance of an alternate discourse suggests if we wish to transform politics, we need to expose our physical, emotional and political scars” (p. 356).

Indeed, RavenLight’s body politics calls into question what remains problematic under the rubric of women, cancer and biomedical “progress,” as much as it also “bespeaks alternative possibilities” (p. 356) and stands as a performative call for action. For in its defiance and vulnerability RavenLight’s body “performs an embodied rhetoric that pushes witnesses to confront what is dangerous to and fragile in the body politic” (p. 357). Through performing resistance there is a disruption of master narratives, dominant rhetorics, and the
standard story of breast cancer. Resistance and disruption can also be brought together in autobiographical performances that undertake to trouble and question, consciously and unconsciously, how we come to perform as patients within the complex system of biomedicine.

7.3 Performing Disruption

Linda Park-Fuller’s (2003) autobiographical performance piece and one act play, “A Clean Breast of It,” engages the personal dynamics of breast cancer diagnosis and treatment while also illuminating the complexity of performing patienthood. Importantly, this solo performance enacts first, and foremost, breast cancer patienthood not survivorship. The script, while first drafted in 1993, is in process as Park-Fuller has modified it during and after performance over the years, and continues to do so (p. 217). Temporally, the timeframe of the play is situated in the present moment of diagnosis and treatment. It is also, necessarily, a retrospective look at Park-Fuller’s experience of being diagnosed and treated for breast cancer in the late 1980s. This performance of personal narrative aims to oppose agnotology, or the study of the cultural production of ignorance, for the play is a manifestation of sharing patient-centred knowledge claims as it aims to educate its audience about the realities of breast cancer from an experiential perspective.

Park-Fuller (2003) has performed “A Clean Breast of It” over fifty times in settings ranging from hospitals to hotel conference rooms, church sanctuaries to manufacturing plant resource rooms, libraries and community centres to university classrooms and lecture halls as well as theatre stages (p. 215). “Three dynamics operated in the formation of this piece: an educational impulse, a sociopolitical impulse, and a performative impulse” (p. 215). Initially,
she wrote against the silence surrounding breast cancer; she wrote to resist and disrupt—to upset the absolute knowledge of biomedicine and to infuse it with the personal dimensions of the disease—as well as to subvert the dominant cultural mythology of the disease (p. 215). Rather than embodying what she recognized then as the prescriptive passive role of the cancer patient as “victim,” Park-Fuller first wrote to exercise agency, to highlight the fact that she had survived, and to attempt to make some change at the sociocultural level. While she initially adopted the performative role of “survivor,” it was a differently nuanced performance than the one most often performed in the current historical moment. Through the act of writing and revising her own story she has come to understand her performance as actor and agent in her own story, as well as patient and survivor. In this way, the “piece functions performatively to recompose my subjective identity” (p. 215) rather than, for example, having the categorical identity of “breast cancer survivor” function as an inspiration to draw from easily. Finally, Park-Fuller says, she wrote to “desubjectify” her “experiential identity” (p. 215). In other words, in constructing a performance of patienthood from the agentive position of survivor, the performance of breast cancer patienthood became less about translating her actual experience of the disease, and more about the complexity of how to perform this role in an effective emotional and political way for an audience who may be more or less familiar with the cultural politics of breast cancer.

In many significant ways, “A Clean Breast of It” is quintessentially a disruptive breast cancer narrative, and this is poignantly illustrated when the performance is, literally, disrupted every thirteen minutes. Park-Fuller (2003) sets a timer to interrupt her own performance to illustrate that in the United States every thirteen minutes a woman dies from breast cancer. “As a social-medical critique,” this disruption “sharpens our comprehension of
how many people die from the disease and how little progress has been made against it” (p. 218). This aesthetic strategy of narrative disruption also functions to symbolise “the themes of life’s interruptions and improvisations” (p. 218), especially because Park-Fuller cannot predict exactly when the timer will go off in performance. “Like the cancer that occurred so unexpectedly, forcing me to stop, reevaluate and revise my life, so the sounding of the timer forces me to stop and revise my performance” (p. 218). The timer also evokes an “ethical awareness,” as Park-Fuller describes it, for the disruption of the timer calls to mind the “others whose stories do not end as fortunately as mine” (p. 218). “Their stories are not heard within the frame of my performance” Park-Fuller says “but drawing attention to their absence reminds audiences that someone had a different story that will never be told” (p. 219). By disrupting what could be framed as the survivor’s narrative, the timer’s insistence on vivifying the death of a woman with breast cancer can, in Park-Fuller’s estimation, grant the power “to contradict my story” to “those who cannot tell their own” (p. 219). In this way, the stability of the survivor’s narrative is necessarily destabilized through performance, and the focus is placed back on how Park-Fuller performs patienthood in the present tense, rather than offering the easy solution that everything will turn out just fine in the end. “All life is improvisational. Nothing is ‘fixed.’ Everything is subject to interruption and revision” (p. 217). In sum, “the piece attempts to transcend the ‘merely personal’ in personal narratives” because in “A Clean Breast of It” the autobiographical impulse is to “to stand with, not to stand in for, others’ stories” (p. 219).

“Despite its descriptive label, all ‘solo performance’ involves and implicates others,” Park-Fuller (2000) argues in her theoretical work on the staged personal narrative (p. 29). While the individualist notion of “solo performance” may lean towards a reading of the
singly autobiographical aspects of such a performance, just as much attention should be paid to the others one can problematically be understood to speak for. While performers who embody characters or narrators of the fictional imagination, “or speakers who embody personae and political landscapes different from themselves and their own situation” (p. 30), can be understood to enter a complex representational terrain, so too do autobiographical performances. Only in a limited sense are autobiographical performers “relatively free from the ethical dangers of performing others” (Park-Fuller, 2000, p. 30), because only in a certain sense do they perform from the perspective of a wholly individual experience, even though they may claim to only speak for themselves and their subjective experiences, and no one else’s. “I may claim that I do not ‘speak for others,’ but I am someone who speaks, and thus it is my story and my embodied meaning that is offered and not that of another” (Park-Fuller, 2000, p. 31). This situation has the potential to undermine any claim that in solo performance one only performs experiential knowledge. For the purposes of my overall argument in this project, and especially in relation to the telling of autobiographical breast cancer narratives, it is important to remember that, “If my telling silences others’ opportunities to tell, then I may inflict a kind of discursive assault on them” (pp. 31-32). This is especially so if performative autobiography is understood to function as a form of testimony that then claims to unproblematically represent an entire group of diverse individuals. All of this is important to remember because, paradoxically, “In breaking silence and speaking one’s own story of oppression, then, the autobiographical performer risks silencing and oppressing those whom he/she represents” (p. 32). Even if a performer does not intend to silence others, there is always a risk that in telling one’s story it may be perceived by audiences to override or obfuscate the personal narratives of others.
While it may appear that solo autobiographical performances allow for the avoidance of representational issues—of who speaks for whom, when and how—Park-Fuller (2000) suggests that in actual fact these performances only reveal the complexity of such issues (p. 30). “Much of the power of performative autobiography lies in representational issues, in that the performer represents a dissenting, minority, or silenced group with which he/she shares experience” (p. 30). The “transgressive autobiographical narrative” or disruptive personal narrative of breast cancer, “when cast in the form of artistic performances, may be relatively less susceptible to recuperation by the dominant discourse” (p. 30), because the performers structure disclosure, exercise control over the presentation, and speak without the interference of experts (p. 30). But rather than obfuscating responsibility to others, these performative autobiographies can evoke a further responsibility to others—to both the stories of others and by extension to audience members. “To speak publically, on stage, of private experience, or to view publically someone’s personal transgressive story…is to rupture traditional theatrical and rhetorical conventions—causing fractures in the categories of real and fictional, public and private, authorized and subversive” (Park-Fuller, 2000, p. 31). In this instance, both the performer and the audience member are affected by the “force of such categorical collisions,” leaving both bodies “without the protection of their respective roles and comfortable categories” (p. 31). As a result of this exchange, both performer and audience may be left positively “unsettled, inspired, exhilarated, and disrupted” (p. 31). Off stage, the performance of patienthood may also enact such a categorical collision, even if performances may also operate in rather predictable ways. As Park-Fuller argues, “in performing my story, my autobiographical ‘selves’ operate both in concert and contradiction” (p. 32).
The performance of patienthood can be made both familiar and de-familiar through rehearsal, improvisation, and enactment. Performing patienthood also calls to mind the many ways of interacting with—or performing for—not only doctors, nurses, and medical office personnel, but also family, friends, and acquaintances with similar and dissimilar diseases and illnesses. In the act of performing patienthood we must negotiate the complexities of living in a sociocultural world that almost totally subscribes to narratives of “the cure,” “mythic thinking,” and “triumph” and often absents the various complex and disabling features of living through and with illness.

7.4 Performing Patienthood

When I say “we,” make no mistake, I include myself in the ranks of the unwell. Here, as I attempt to engage in my own performative autobiography, illness narrative, and experience of the politics of performing patienthood, I am acutely aware of how difficult it is to tell an iteration of one’s story so that it sufficiently stand with, and not in for the narratives of others who have also experienced life altering illnesses. The problem, in part, is the sheer discursive dominance of standardized story telling and the immense narrative pressure I feel, as a “wounded storyteller” (Frank, 1995), to tell a version of the “triumph narrative” (Conway, 2007) when translating my embodied reality to others—even though the narrative trope of “triumph” is completely outside my experiential knowledge of disease. We must, then, attempt to resist normative narratives—and to do this, in part, by employing self-reflexive writing practices—in order to resist creating oppressive narratives. In the process of constructing this story I am acutely aware of the ways in which I perform patienthood. Over the last few years I have assembled a set of performance practices in order to better negotiate
the biomedical system, and my seeming ability to navigate this system is not incidentally connected to certain concrete instances of privilege.

I have learned—through trial and error—to perform in the clinic for doctors in a way that signifies “good patient,” as in agreeable, trustworthy and compliant, rather than “bad patient,” as in difficult, negligent and time-consuming. In my tenure as patient, I have learned to always ask for copies of all medical lab tests and the routine yet seemingly easy to misplace or misfile correspondence between the doctors on my treatment team. Therefore, I have also assembled a copy of my own medical file, because in learning to first become a patient, then a “good patient,” and subsequently to perform patienthood in the clinic in such a manner, I have come to understand that I am ultimately responsible for facilitating a sharing of information between my family physician, clinical specialist, and two surgeons. I admit that this situation may not be what the system intends, but in the current neoliberal moment of biomedicine in the province of British Columbia the patient bears much responsibility in translating information from Endocrinology to Ophthalmology to Otolaryngology and back to General Medicine. I have read letters that describe me as a pleasant young woman and PhD Candidate, in addition to describing my overall physical health and the current state of the autoimmune disease I embody. I understand that these specialists are attached not only to trying to restore my previous good health, but also my physical appearance which has been not insignificantly affected. But I cannot say I am altogether comforted by this, because it also makes me extremely aware that my perceived gender, race, sexuality, class, ability, and age are performed in the clinic in ways I have little control over. What I am attempting to explicate here is that it is not incidental that I am able to successfully perform the role of “good patient,” because I am unproblematically seen as female and feminine, white,
heterosexual, middle class, “high functioning,” and young. What I am also attempting to point out is that this way of being seen would most surely fall apart if I were asked instead to describe my understandings of self through personal narrative.

What should also be obvious is that I am privileged in terms of acquiring higher education—something I have earned—versus whiteness—a completely unearned privilege and one I attempt to undo. Nevertheless, I have learned over the course of my tenure as patient that in order to be referred to the best clinical specialists, and to receive the best available treatments, the good patient must carefully balance a performance of advocacy while never giving the impression that expert knowledge is being dismissed or disregarded. Because this particular narrative of experiential knowledge is situated in the context of the Canadian medical system, one must also be prepared to wait, and then wait even longer, to see certain specialists and surgeons. By the time I do receive an appointment, I nearly always enter the clinic armed with a memorized and written list of needs, wishes, and wants, such as different or additional blood tests and medications, modifications to my treatment plan, an opportunity to discuss the possibility of one kind of surgery over another. Learning the “correct” terms, or rather deploying medical language and terminology and talking to medical doctors in their own language, can, it seems, garner a certain amount of respect so as long as one does not make a mistake. Upon reflection, I am astounded that I have had not only to learn a new language but acquire an incredibly large amount of medical information in order to simply navigate the medical system in a way that feels complete and comprehensive, all the while performing as a “good patient” should—obedient, diligent, respectful. At times, this project of performing patiency has amounted to the worst kind of part-time job—time consuming and dull—and I have the research skills needed to bolster and
perfect this performance. There is something distinctly unsettling about this situation, and as an advocate for social justice I firmly stand in solidarity with all patients: past, present, and future.

I have gotten angry—really angry—at institutional delay and what feels like the indifference of a medical system where as patients we are cases, numbers, and diseased bodies, not subjectivities with feelings, wants and needs. In turn, I have witnessed the extreme frustration of doctors unable to sufficiently advocate on my behalf to administrators within the system. I have listened to doctor’s narratives, stories I later promised never to repeat, and witnessed what some doctors will do in order to ensure their patients get the very best treatment plan or surgery when the Medical Services Plan of British Columbia is unwilling to pay out. But I am not trying to restore or instil an antiquated sense of belief in the doctors who work within biomedicine. To be sure, I have dumped a few crappy doctors over the course of performing patienthood. I am only strategically a “good patient.” But I have also been reminded of how both doctors and patients perform in a system ultimately not of our own design and the practices within biomedicine, not unlike illness narratives, as Diedrich (2007) reminds us, inevitably embody many sites of failure. As Audre Lorde (1981) suspected, I have “a well-stocked arsenal of anger potentially useful against those oppressions, personal and institutional, which brought that anger into being” (p. 127), and I am more than happy to deploy this anger in the service of a particular performance of patienthood—“the politicized patient” (Diedrich, 2007, pp. 24-53). To be sure, I am deeply disturbed—emotionally, intellectually, politically—by rising cancer rates in Canada. I curse governmental inaction, especially if it could potentially protect the vulnerable—children, workers, and citizens—from environmental toxicants and carcinogens. Like Wendy Mesley
(2006), I am shocked that one in two Canadians will be diagnosed with cancer within their lifetimes. Like her, I believe that this statistic is not only disturbing, it is a sign that collectively we must work towards changing it.

Because I live with “the little c” of chronic illness, not the “the big C” of cancer, perhaps I have been spared some of the more insidious storytelling of the redemptive power of illness, rumours, I am convinced, that could only have been started by a healthy person. Instead, I know of some of the ways in which one is medicalized and something of how odd it feels to be queer in the excruciatingly heteronormative world of biomedicine. I know the look of confusion and then what amounts to pity when I assure nurses I am attending my appointment alone and that I have neither next of kin nor family living in the city. I know of being very much alone practically, financially, emotionally in facing disease and some of the most difficult diagnostic procedures and treatments, and how quickly this all can become precarious. Surely, there are so many others in my very situation if only we look a little closer and little more critically. Of course, this affective terrain has influenced the ways I perform the politicized patient. This sort of experiential knowledge does more than signal the alarm, then anger and rage, I first felt when learning that biomedicine can control the symptoms of autoimmune disease but does not know how to interrupt and treat the autoimmune reaction. If autoimmune disease is a silent epidemic, why is so little clinical research being conducted to investigate the root cause or causes of a misfiring immune system? I wish I could join what Arthur Frank (1995) terms “the remission society” (p.156), because at least then this disease would actually be in remission. But in the end, the performative impulse of my own anger has engendered what amounts to compassion. Compassion not only towards the many working within biomedicine who are true allies and
advocates of best practices when it comes to patient care—recognizing that the medical system often works extremely well in times of acute crisis but functions less than perfectly when disease shifts from acute to chronic—but towards my fellow patients. We are part of a club no one ever willingly joins. Illness has changed me, but not in the ways standardized storytelling and the epideictic discourse in the study of illness narratives might wish to prescribe. I am changed because I now I stand in solidarity with those who have experienced life-altering illnesses and disabilities. As someone who is also forever changed by illness, in the ways only experiencing serious disease can change a person, I am changed. But make no mistake: this is not a triumph narrative.

Now, I wonder if it would be best not to bring this particular illness narrative into this particular project, for surely I have not faced a cancer diagnosis and, truly, I do not want my experiential knowledge of illness to be compared to the knowledges of the many women in the breast cancer narratives I have studied. For to do so would not only be deeply misguided, it would be deeply disrespectful in the way false comparisons are. Let me be clear: I do not know what it is like to suffer through the kinds of chemotherapy treatments where one feels dramatically worse before one has a chance to feel better. I do not know what it is like to be given a diagnosis where one must witness the palpable fear in others before even having a chance to process one’s own sense of mortality. But I do know something of the disappointment, interruption, and discontent illness can impart. I know of the many contours of feeling that surround preparing for and having major surgery and of experiencing the vulnerability and pain of recovery. And I do know something of how smart and savvy we as patients can become in narrating and performing, constructing and deconstructing, learning and creating new knowledges out of our own illness experiences, all while hoping it might
have some critical utility, the way any tool should, for others. I know something of hoping that my story might be just disruptive enough to make some ripple, some amount of change in the world of illness culture.

To be sure, in turning to personal narrative I do so not because it is the most readily available or accessible genre for me as a writer and patient to employ. Rather, I do so because it makes me profoundly uncomfortable. I am conscious of not over-personalizing this narrative, not only because it would be rather boring for me to write, but also, I think, rather boring to read; it would not serve the purposes of this particular telling. If autobiographical performativity is about desubjectifying personal experience in narrative form, rather than aspiring to find the true essence of self and experience through storytelling, perhaps another sort of narrative tool emerges in so doing. But first, the context of the telling of this story is very important. For there can be much to lose in outing oneself as unwell and certainly the university can be a distinctly unsafe place to do so, as Kimberly R. Myers (2004), Ellen Samuels (2003), and others have cogently argued. From my perspective, outing oneself in academia can become a precarious reality, for there is nothing to be gained from outing oneself as unwell and everything to lose in terms of the respect of others and their confidence in your physical and cognitive abilities. As Myers (2004) clearly articulates, there is a distinct power politics at play in coming out as sick in academia, because the academy, not unlike contemporary society at large, can be understood to strive to obscure the vulnerability of the body. But there might also be a queerly oriented and defiant sort of empowerment to be had, as Robert McRuer (2006) argues, in coming out as “crip”—queer and dis/abled and/or queerly dis/abled. To be sure, no matter the kind of performance of patienthood we enact, we do so in contexts implicitly bound up in systems of power.
Performing patienthood can be an embodied act of precarity, while it can also be a loud and highly visible one.

I currently have the ability to strategically perform certain aspects of patienthood while downplaying others. This is because my symptoms are currently controlled by medication. I can perform as a high functioning sick person, and I can pass as well, but for reasons both personal and political I am not interested in doing so. Perhaps there is nothing more confusing, especially for those who have not yet used the passport that grants one entry to what Susan Sontag (1990) describes as “the kingdom of the sick” (p. 1) as that of “invisible” illness and/or disability. “Illness,” she said, “is the night-side of life, a more onerous citizenship” (p. 3). I realise that deeply bound up in the act of passing for well are instances of privilege, as much as I am also aware that my particular performance of patienthood may be of the more temporary variety, rather than a permanent act I can call on whenever I wish. Should my symptoms get markedly worse as suddenly and spontaneously as when the disease first became manifest, it would be nearly impossible for me to hide the fact that I am unwell. And I would be several dollars richer if I had a dollar for every time I have heard something that amounts to the keen observation that I do not “look” sick. However, I am tired of tired clichés to describe not only a personal situation but a political one, in the culture of illness that is far more complex than whether one “looks” unwell or not, and is more about who deems themselves entitled to freely offer this unsolicited assessment. Now, and for the foreseeable future, I perform patienthood in the present tense. This counternarrative aims to do a kind of countercultural work that could not be done in any other genre. It aspires to a manner of repair, as it not only aims to illuminate my own
particular and contingent investments in this academic project, but also to enact a sort of repair in relation to my own illness narrative and a subjectivity changed by illness.

7.5 Performing Narrative Repair

Illness is not something some are immune to, while others will fall sick. There is a potentially damaging narrative circulating through dominant discourses of health and wellness, where disease is understood to be the manifestation of the lack of proper individual monitoring, care, and responsibility. In other words, disease manifests because of something an individual *did or did not do* to their bodies. It is the sick, we are also instructed, who then use up the available healthcare resources in what we are told is a Canadian medical system already overburdened by patient demands. I am one of those who presumably overuse the system (even though I have been required to pay out of pocket for some, but not all, of my treatments), because when it comes to crude numbers I am in a doctor’s office at least eight times a year, and, often I am there at least once a month. It is very easy to add up the appointments when one’s condition necessarily requires regular monitoring. Perhaps I should not mention the monthly visits to the lab for blood work. But then I have never been a fan of the “blame game” and I like the “shame game” even less.

I will admit that something cuts inside me when I am subjected to master narratives of illness—often with an accompanying assessment of sick people who choose to use the medical system rather than rely on something akin to prudent self-care and home remedy—not only because they are so often false, but because I am sick too. Sontag argues

> Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we prefer to use only the good passport, sooner or
later each of us is obliged, at least for a spell, to identity ourselves as citizens of that other place. (p. 3)

Dominant narratives of health and wellness do not truly attempt to engage with the complexity that disease manifestation presents. These narratives are not interested in a patient’s own understanding of why they have fallen ill or how best to treat the disease. But then I am not invested in uncovering exactly why or how disease or illness might come to manifest in individual bodies or how best to treat it, as much as I am extremely interested in the stories we tell of illness. I want to stress here that dominant narratives of illness have the potential to do further harm to already “damaged identities” (Nelson, 2001). Conversely, I have found that certain illness narratives—disruptive breast cancer narratives to be sure—have the potential to perform “narrative repair” for damaged identities. For when we identify ourselves as citizens of that other place—“the kingdom of the sick” (Sontag, 1990, p. 3)—when we remark upon its side streets, back alleys, gutters and the performances we must deploy to make our way through this strange land, we contribute to archives of feeling and knowledge. Here, personal narrative is deployed in an attempt to share and create new experiential knowledges. Such counternarratives might also function not only to provide a type of narrative repair in correcting false stories of illness, but also work in particular instances to heal those subjectivities understood as unwell.

As Nelson (2001) argues, “the immediate purpose of a counterstory is to repair identities that have been damaged by oppression” (p. 20). She reminds us that “identities” are complex narrative constructions consisting of a fluid interaction of the many stories and fragments of stories surrounding the things that seem most important, from one’s own point of view and the point of view of others, about a person over time. (p. 20)
Identities are damaged when powerful institutions and individuals view “others” as morally, emotionally or physically “abnormal” and prevent such individuals from occupying places and spaces within society that are “identity-constituting” (p. 20). Harm to already oppressed identities is enacted through further “deprivation of opportunity” (p. 20), and the counternarrative response functions to change this perception and to demand some manner of social justice. Here, illness narratives can take the form of a counterstory about the sick and/or disabled person and position this person as an active participant in sociocultural life rather than a passive recipient of medical care. Those diagnosed and treated for breast cancer can write a counternarrative, resisting the notion that cancer is in any manner okay—politically, culturally, physically, and/or emotionally—rather than narrating yet another version of cancer’s standard story. Perhaps the most insidious impact of oppression and the most damaging aspect of the narrative damage enacted through master narratives, is the damage done to subjectivities through “infiltrated consciousness,” whereby the Oppressed come to internalize “the hateful or dismissive views” of others (p. 21). Nelson offers a possible solution to this damage, explaining that “because identities are narratively constructed and narratively damaged, they can be narratively repaired” (p. xii). The type of counternarrative needed to repair a damaged sense of self is the counterstory the ill person self-constructs and performs in self-repair, changing both a damaged subjectivity and damaged self-perception.

Narrative repair, then, is complex and multifarious as much as it is the purposeful and wilful act of attempting to mend, fix, or stitch back together that which was torn apart or ruptured—bodies, selves and narratives. Narrative repair is neither a simple nor a singular act, for it is a process of doing and redoing. Mary Bryson (2009) reminds us that we may be
rather familiar with the quotidian meaning of “repair” in academia, because as researchers
“we fix our gaze on broken things, diagnose the cracks, anomalies and fissures and set out to
set things straight” (para. 5); repair is synonymous with restore, remedy, renew and revitalize
(para. 4). But a secondary definition of repair, since its etymology references repatriation, is
also suggestive of “movement;” repair is reiterated as “repetition, with habitual engagement
and with an open-ended understanding of temporality” (para. 6). Repair as active and
relational and “recast as [p]erforming [r]epair,” Bryson argues, “changes the stress entirely
from one of the management of impairment, to the mobilization of capacities” (para. 5). The
“performativity of repair adds further critical layers since it suggests that one cannot take
repair for granted—that it is enacted” (para. 10). That is, repair is not just enacted in
language, it is also performed. Beyond considering the everyday meaning of repair, or its
secondary associations with performativity and performances, Bryson suggests exploring the
daily “complexity of the enunciatory possibilities—the poiesis—of repair” (para. 2). To
explore the poiesis of repair, then, is to explore repair as a doing, a “making,” and a narrative
endeavour. To perform repair is to participate in remaking body, self, and narrative, for we
are constituted in and through stories, as illness narratives—especially disruptive breast
cancer narratives—so poignantly illustrate.

In a future program of research, I intend to pursue the potential of narrative repair in a
project that brings personal narratives of chronic illness and breast cancer together, for as
Abel and Subramanian’s (2008) research stresses, in particular cases breast cancer must be
reconceptualised as a chronic illness. The women diagnosed and treated for breast cancer in
Abel and Subramanian’s study, and chronicled in the text After the Cure: The Untold Stories
of Breast Cancer Survivors, spoke of fatigue, chronic pain, insomnia, depression, and chemo
brain long after treatments concluded. Often these symptoms were debilitating, negatively impacting quality of life as well as mobility and ability. My research project will include the personal narratives of those diagnosed and treated for breast cancer and experiencing post-treatment symptoms, who self-describe as chronically ill. In their edited collection of women’s autobiographical writing on chronic illness, Diane Driedger and Michelle Owen (2008) poignantly term such illnesses “dissonant disabilities,” a powerfully evocative and theoretically suggestive description. It is my contention that chronic illness—as a dissonant disability— not only requires further study from interdisciplinary frameworks, but also demands new ways of theorizing the body that intelligently address bodily uncertainty, unpredictability and disruption. As a result, the theoretical framework for this research remains rooted in intersectional feminist theory and narrative bioethics, but will also explicitly draw from both queer theory and disability studies.

There is much to be gained from investigating how these two fields are brought together in the emergent terrain of “crip theory” (McRuer, 2006; Kafer, 2003), which brings concepts of “compulsory abled-bodiedness” (McRuer, 2006) and “compulsory heterosexuality” (Rich, 1980) together. In fact, crip theory may be a particularly poignant way to explore the contested terrain of “invisible disability,” because chronic illness often presents as not only a misunderstood illness, but also an invisible one (Wendell, 2001). Additionally, Pamela Moss and Isabel Dyck (2002) propose a “radical body politics” to better understand how the material and discursive realities of the body dictate the ways in which women with chronic illnesses negotiate the physical sites of everyday life (p. 9). Yet what can be understood as truly radical about such a reconceptualization of body politics is that the chronic nature of chronic illness must be examined in relation to dominant discourses
that understand illness as “acute” or “disabling,” but not “chronic” and thus “unpredictable” and “continuous.” Chronic illness defies conventional biomedical understandings of illness, where one is diagnosed and then inscribed as either sick or healthy because “chronic illness is about being both sick and healthy—at the same time” (Moss & Dyck, 2002, p. 14). Chronic illness breaks apart the dualism of “healthy” or “sick” because chronic illness is a “long-lasting sickness with no definitive cure” or a “condition of infirmity” or “lack of health” (Moss & Dyck, 2002, p. 16). But these descriptions of chronic illness neither describe the intensity of living with chronic illness nor the complexity of living with an unrelenting state of bodily uncertainty. In my future research, then, I intend to shed light on this complex corporeal reality by turning to published personal narratives that endeavour to describe the particularities of specific chronic illnesses as well as perform a manner of narrative repair in undertaking this important cultural work in the world of biomedicine and illness narratives.
References


<http://www.ccfi.educ.ubc.ca/publication/insights/v13n02/intro/welcome.html>


<http://www2.macleans.ca/2008/11/20/the-angry-breast-cancer-survivors/> Retrieved
10 June 2011.

Minneapolis, MN: University of Minnesota Press.

communication, 25, 286-289

King, S. (2010b). Pink Ribbons Inc.: The emergence of cause-related marketing and the
corporatization of the breast cancer movement. In L. Reed & P. Saukko (Eds.),
Governing the female body: Gender, health and networks of power (pp 85-111).


activism. Minneapolis, MN: University of Minnesota Press.


Liljeström & S. Paasonen (Eds.), Working with affect in feminist readings: Disturbing

performances quarterly. 9(4), 243-276.


Segal, J. (2010, April 1). Cancer isn’t the best thing that ever happened to me. Vancouver Sun, pp. A15.


