

# Counternarratives of Breast Cancer and Chronic Illness

## Performing disruption, patienthood and narrative repair

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### 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. (Ehrenreich 2001: 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' (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' (50). In framing breast cancer culture as a cult, or even a 'full-fledged religion', Ehrenreich explicitly troubles what has grown 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 [acquired immunodeficiency syndrome], cystic fibrosis, or spinal injury, bigger even than those more prolific killers of women – heart disease, lung cancer and strokes' (45). Certainly, as she stresses, 'Now breast cancer has blossomed from wallflower to the most popular girl at the corporate charity prom' (45). 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 that one may expect from a culture formed around such a women's health issue. Her 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 that we live in a time that has moved beyond patriarchal biomedicine, 'obedience is the message behind the infantilizing theme in breast-cancer culture' (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' (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' (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' (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. Instead, she wrote a disruptive breast cancer narrative. For the mainstream 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.

Often 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 and knowledges about the breast cancer experience. In order to expressly situate breast cancer as a cultural formation, we may employ the phrase 'breast cancer culture' with the intention of retaining 'the complex variety of meanings associated with the word *culture*' (King 2006: 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 (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 (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 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: 6) – by refuting the master narrative and telling instead a different version of what heretofore may be understood as 'socially shared understandings' (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 2007: 4). This story insists 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' (6), and they are used not only to make sense of experience but to 'justify what we do' (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' (6). These stories 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' (8). These stories are 'developed for the express purpose for resisting and undermining an oppressive master narrative' (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' 8). This allows the teller of a counterstory 'to dissent from the interpretation and conclusion it invites' (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' (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 may 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. 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, as the teller also refuses to perform the master narrative of breast cancer in the quotidian realities of the day to day.

#### 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. It also functions as a counterstory and a disruptive breast cancer narrative. Importantly, this solo performance enacts first, and foremost, breast cancer patienthood and not survivorship. The script, while first drafted in 1993, is constantly in process, as Park-Fuller has modified it during and after performance over the years, and continues to do so. 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 inform its audience about the realities of breast cancer from an experiential perspective.

Park-Fuller (2003) has performed *A Clean Breast of It* more than 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. 'Three dynamics operated in the formation of this piece: an educational impulse, a sociopolitical impulse, and a performative impulse' (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 (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 writing and revising her 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' (215) rather than, for example, having the categorical identity of 'breast cancer survivor' function as an easy inspiration to draw from. Finally, Park-Fuller says that she wrote to 'desubjectify' her 'experiential identity' (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 13 minutes. Park-Fuller (2003) sets a timer to interrupt her own performance to illustrate that in the United States every 13 minutes a woman dies from breast cancer. 'As a social-medical critique', this disruption serves to sharpen 'our comprehension of how many people die from the disease and how little progress has been made against it' (218). This aesthetic strategy of narrative disruption also functions to symbolize 'the themes of life's interruptions and improvisations' (218), especially because Park-Fuller cannot predict exactly when the timer will go off in the 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' (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' (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*' (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' (219). In this way, the stability of the survivor's narrative is 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.

'All life is improvisational. Nothing is "fixed." Everything is subject to interruption and revision' (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 stand with, not to stand in for, others' stories' (219).

'Despite its descriptive label, all "solo performance" involves and implicates others' argues Park-Fuller (2000) in her theoretical work on the staged personal narrative (29). While the individualist notion of 'solo performance' may lean towards a reading of the singularly 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' (30), can be understood to enter a complex representational terrain, so too do autobiographical performances. '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' (31). This situation has the potential to undermine any claim that in solo performance one only performs experiential knowledge. Especially in relation to the telling of autobiographical breast cancer narratives, it is important to remember, 'If my telling silences others' opportunities to tell, then I may inflict a kind of discursive assault on them' (31–2). 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' (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 (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’ (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’ (30), because the performers structure disclosure, exercise control over the presentation and speak without the interference of experts (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’ (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’ (31). As a result of this exchange, both performer and audience may be left positively ‘unsettled, inspired, exhilarated, and disrupted’ (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’ (32).

As such, 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’ and ‘triumph’ and often absents the various complex and disabling features of living through and with illness.

#### 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 stands 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 storytelling 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 outside of 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 laboratory 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, and 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 (BC) in Canada 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 and 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 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 also 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 patienthood 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.

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 doctors' narratives, stories I later promised never to

repeat, and witnessed what some doctors will do in order to ensure that their patients get the very best treatment plan or surgery when the Medical Services Plan (MSP) 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 how the practices within biomedicine, not unlike illness narratives, as Lisa Diedrich (2007) reminds us, inevitably embody many sites of failure. As Audre Lorde (1980) suspected, I have 'a well-stocked arsenal of anger potentially useful against those oppressions, personal and institutional, which brought that anger into being' (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: 24–53). I am deeply disturbed – emotionally, intellectually, politically – by rising cancer rates. I curse governmental inaction, especially if it could potentially protect the vulnerable – children, workers and citizens – from environmental toxicants and carcinogens.

Because I live with 'the little c' of chronic illness, not '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 that 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 and 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 situation if only we look a little closer and 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, and 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 Frank terms 'the remission society' (1995: 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: 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 that standardized storytelling and the epideictic discourse in the study of illness narratives may wish to prescribe. I am changed because I now stand in solidarity with those who have also 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.

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 (and also, I think, rather boring to read) but because 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.

Currently, 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 describes as ‘the kingdom of the sick’ (1990: 1), as that of ‘invisible’ illness and/or disability. ‘Illness’, she said, ‘is the night-side of life, a more onerous citizenship’ (3). I realize 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 critical essay, but also to enact a sort of repair in relation to my own illness narrative and subjectivity changed by illness.

#### 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 a 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. 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. 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 may come to manifest in individual bodies or how best to treat it, as much as I am extremely interested in the stories that 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 and chronic illness narratives – 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: 3) – and when we remark upon its side streets, back alleys and 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 may also function not only to provide a type of narrative repair in correcting false stories of illness, but also to work in particular instances to heal those subjectivities understood as unwell.

As Nelson argues, ‘the immediate purpose of a counterstory is to repair identities that have been damaged by oppression’ (2001: 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. (Nelson 2001: 20)

Identities are damaged when powerful institutions and individuals view ‘others’ as morally, emotionally or physically ‘deviant’ and prevent such individuals from occupying places and spaces within society that are ‘identity-constituting’ (20). Harm to already oppressed identities is enacted through further ‘deprivation of opportunity’ (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 OK – politically, culturally, physically and/or emotionally – rather than narrating yet another version of cancer’s standard story. Perhaps the most

insidious impact of oppression is the damage done to subjectivities through ‘infiltrated consciousness’, whereby the oppressed come to internalize ‘the hateful or dismissive views’ of others (21). Nelson offers a possible solution to this damage, explaining, ‘because identities are narratively constructed and narratively damaged, they can be narratively repaired’ (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 that 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). However, 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 so poignantly illustrate.

#### REFERENCES

- Bryson, Mary (2009) 'Adventures in deconstruction', *Educational Insights*, 13, [www.ccfi.educ.ubc.ca/publication/insights/v13n02/intro/welcome.htm](http://www.ccfi.educ.ubc.ca/publication/insights/v13n02/intro/welcome.htm), accessed April 21 2013.
- Conway, Kathlyn (2007) *Illness and the Limits of Expression*, Ann Arbor, MI: University of Michigan Press.
- Diedrich, Lisa (2007) *Treatments: Language, politics and the culture of illness*, Minneapolis, MN: University of Minnesota Press.
- Ehrenreich, Barbara (2001) 'Welcome to cancerland', *Harper's Magazine*, pp. 45–53, November.
- Frank, Arthur (1995) *The Wounded Storyteller: Body, illness, and ethics*, Chicago, IL: University of Chicago Press.
- King, Samantha (2006) *Pink Ribbons, Inc.: Breast cancer and the politics of philanthropy*, Minneapolis, MN: University of Minnesota Press.
- Lorde, Audre (1980) *The Cancer Journals*, San Francisco, CA: Spinsters Ink.
- Myers, Kimberly R. (2004) 'Coming out: Considering the closet of illness', *Journal of Medical Humanities* 25 (4): 255–70.
- Nelson, Hilde Lindemann (2001) *Damaged Identities, Narrative Repair*, Ithaca, NY: Cornell University Press.
- Park-Fuller, Linda M. (2000) 'Performing absence: The staged personal narrative as testimony', *Text and Performance Quarterly* 20(1): 20–42.
- Park-Fuller, Linda (2003) 'A clean breast of it', in Lynn C. Miller, Jacqueline Taylor and M. Heather Carver (eds) *Performing Women's Autobiography: Voices made flesh*, Madison, WI: University of Wisconsin Press, pp. 215–236.
- Samuels, Ellen (2003) 'My body, my closet: Invisible disability and the limits of coming-out discourse', *GLQ* 9: 233–55.
- Segal, Judy Z. (2007) 'Breast cancer narratives as public rhetoric: Genre itself and the maintenance of ignorance', *Linguistics and the Human Sciences* 3(1): 3–23.
- Sontag, Susan (1990) *Illness as Metaphor* New York, NY: Anchor Books.