Risk and Responsibility in the Neoliberal State: A Study of Contemporary Illness Narratives

Illness narratives, commonly understood, are autobiographical accounts of sickness and disease written or spoken, most often, by patients. Almost non-existent globally before the 1970s, these pathographies, as with all kinds of other memoirs and life-writing, have become near ubiquitous in modern times. From blogs to full-length memoirs, patients, caregivers, physicians, family members, journalists and academicians have been copiously and scrupulously narrating their experiences of illness. Through the 1980s, the quintessential writeable illnesses, those with the most visibility and narratability were cancer and AIDS.

In the last days of 1971, Richard Nixon signed the National Cancer Act legislating a "national commitment for the conquest of cancer".[i] The first shot of the war on cancer was fired on capital hill. The signing of the national cancer act coincided with a sustained swell in illness memoirs, specifically cancer narratives and even more specifically, breast cancer narratives. In striking clarity, W. Rosamond Campion in *The Invisible Worm* (1972), Rose Kusher in *Breast Cancer: A Personal History and Investigative Report* (1975) and Betty Rollins in *First You Cry* (1976), to name just a few, detailed their diagnoses, disfiguring and painful treatments and often isolating recovery processes. Dirges of sadness, frustration and rage, they were also profiles of courage. These honest accounts seemed to peel away layers of accreted shame as women participated in and advocated for decisions around treatment, especially surgery and subsequent body image. In spite of an overt political agenda and an overwhelming distrust of medical paternalism, most breast cancer narratives of the 1970s chronicled survivorship. The poet Audrey Lorde, described herself as a "black woman warrior poet doing my work"[ii] in her 1980 book *The Cancer Journals,* which blended diary excerpts and scholarly essays to give an account of how she experienced and survived breast cancer, emphasizing her diagnosis, subsequent mastectomy and decision to not wear a prosthesis. Like Lorde, the protagonists of these narratives were often heroes and warriors reflecting the enlightenment belief in scientific empiricism and the eventuality of a cure.

By the end of the decade, the cancer narrative had become so entrenched and pervasive that Susan Sontag could write her own anti-illness narrative *Illness as Metaphor* (1978). Written immediately after undergoing a radical mastectomy and chemotherapy for stage IV breast cancer between 1974-77, Sontag argues that the cloaking of illness in metaphor, the literary obscuration of disease and biology for typology and psychology, silences and shames patients by blaming them for their disease: melancholics get tuberculosis because they are melancholic, while sexually repressed individuals get cancer because they are sexually repressed. Sontag's resistance to metaphor also seems to be a resistance to self as she never mentions her own immediate experience with cancer or her father's death from tuberculosis in 1939. Only while reflecting on her earlier book in *AIDS and its Metaphors* (1989), does Sontag acknowledge this absence: "I didn't think it would be useful—and I wanted to be useful—to tell yet one more story in the first person of how someone learned that she or he had cancer, wept, struggled, was comforted, suffered, took courage...though mine was also that story. A narrative, it seemed to me, would be less useful than an idea".[iii] Despite breaking with the new tradition of confessional accounts, Sontag maintained a belief in the progress of empirical science. As her son David Rieff wrote in his tribute to Sontag, *Swimming in A Sea of Death: A Son's Memoir* (2008), "fighting cancer became…a question of the right information, the right doctors, and the right follow-through."[iv]

On June 5, 1981, the Mortality and Morbidity Weekly Report or MMWR, an epidemiologic publication of the Centers for Disease Control and Prevention (CDC), a federal agency under the Unites States Department of Health and Human Services tasked with protecting and promoting public health, reported the first five cases of PCP pneumonia and cellular immunodeficiency in what would later be recognized as patients with AIDS.[v] It was not until 1985 that any effective treatment, AZT, would be available and it would be another two more years before the president of the United States would make his first official comments about the epidemic. Almost five years for any effective treatment and almost seven years of official silence. In that time more than 12,000 people died of AIDS related complications in the United States.

Against this backdrop of untimely death, official silence and seeming scientific bafflement, people dying of AIDS, their family members and caregivers wrote. They wrote narratives, letters, diaries, plays and novels. And they didn't stop writing.

They wrote to catalogue their symptoms, what Paul Monette in *Borrowed Time: An AIDS Memoir* (1988) called "the particular indignities of AIDS";[vi] they wrote as witnesses to their own deaths; they wrote to counter prevailing attitudes of homophobia; they wrote to educate an unsuspecting, ignorant and fearful populace. They wrote to fill the silence. ACT UP, the AIDS coalition to unleash power, explicitly highlighted the political value of language and writing in their slogan, "Silence = Death."[vii] Despite the slow pace of scientific discovery and the failures of our public health system, the politics of AIDS activism and the proliferation of AIDS narratives all suggest an abiding faith in knowledge and science: As Monette again writes, "[We] became postgraduate students of the condition. No explanation was too technical for me to follow…In school I'd never scored higher than a C in any science, falling headlong into literature, but now that I was locked in the lab I became as obsessed with A's as a premed student. Day by day the hard knowledge and raw data evolved into a language of discourse" (92). People with AIDS self-educated themselves, got masters in biochemistry and epidemiology, formed scientific reading groups, conversed regularly with physicians and scientists and even conducted clinical trials. They became establishment experts and believed that the way to a cure was through greater funding of scientific research.

The optimism and fanfare of the war on cancer has met with a sobering reality: between Nixon's signing of the National Cancer Act of 1971 and now, the overall mortality from cancer, notwithstanding a few fabulous successes like childhood leukemia, has remained practically unchanged.[viii] And while the initial failure of the national public health system in acknowledging the AIDS epidemic was overcome by the development of highly active anti-retroviral therapy (HAART) and a falling mortality rate, the rate of new infections remains stubbornly constant with certain subgroups bearing a disproportionate burden of disease. Even as HIV infection has become more of a chronic disease in the Unites States with lifespans reaching the average for non-infected peoples, though a significant discrepancy still exists for non-whites, HIV/AIDS has become a global problem, with more than 35 million cases worldwide, of which 25 million are in Subsaharan Africa alone.[ix]

Most studies of illness narratives tend to valorize coherence and continuity, of both narrative and identity. In one respect, it is the triumphs of modern medicine that make illness narratives possible. Lives that otherwise would have been cut short by illness and death are prolonged. But cure has often been elusive and with the rise of chronic illness, most survivors live in what the sociologist Arthur Frank has termed the "remission society."[x] As medicine has become more consistently efficacious, it has increasingly disengaged from questions of meaning, fragility and impermanence. Illness narratives offer a complement to the medicalization of disease in which personal meanings, stories and metaphors can be developed while the dehumanizing tendencies of the medical establishment can be resisted. If illness is experienced as a catastrophic disruption of identity, the work of writing for members of 'the remission society' is to suture the before and the after, to realign the past, present and future. As it seems to have been for Audrey Lorde, illness can be understood as primarily an intensification of the past. Lorde's breast cancer and eventual mastectomy is another in the long line of differences that have made her her: "I'm defined as other in every group I'm part of," she writes.[xi]

But in the contemporary time of fragmentation, distrust of authority, rejection of grand meta-narratives like Science with a capital 'S', and neoliberal economic policies that have ushered unfettered disaster capitalism, illness narratives seem to have shifted their focus. If cancer and AIDS were the most representative subject in the 1970s and 1980s respectively, our contemporary times have seen the rise of a new kind of illness narrative, what I will call the reflexive risk narrative adapted from Ulrich Beck's term *reflexive modernism.* In *The Risk Society,* Beck outlined "the new paradigm of risk society" that was no longer exclusively based on the distribution of wealth in terms of social class but on the "distribution of techno-scientifically produced risks," specifically "the industrial pollution of the environment and the destruction of nature."[xii] He contrasts a "scarcity society" with a "risk society"; the first is primarily concerned with managing genuine material need while the latter's concern is how to distribute, limit and prevent the risks systematically produced as part of the modernization process itself, a process he calls *reflexive modernization.* The risks are inherently different from risks experienced in prior eras for a number of reasons: They are global (i.e. untethered to their place of origin, catastrophic in scope, incalculable in effect) as opposed to local; they "escape perception and are localized in the sphere of physical and chemical formulas" (21); they are a product of industrial overproduction; they are the direct result of the modernization process: global warming from greenhouse gas emissions, the threat of nuclear fallout and radioactivity; pesticides in our foodstuffs.

In a risk society, everyone is at risk ("poverty is hierarchic, smog is democratic" [36]), or in the term of medical narratives, everyone is a previvor. In reflexive risk narratives, anyone can be an author, there are no experts, causality and ontology are always in question, a cure never seems like a possibility, and because risk is always present, there is no clear before and after. Reflexive risk narratives are centered on the risks to the body and health from modernization and modern medicine: autism from a surfeit of visual stimuli and vaccines; childhood obesity from sedentary videogame lifestyles and a corporate fast food industry that counts profits in terms of calories; cancer from bovine growth hormones in our milk and multiple power lines crisscrossing above our small towns. These proliferating narratives all seem to affirm the question, ripped from the headlines of countless newspapers, magazines and tabloids, "Are we making ourselves sick?"

In the next section I want to discuss a strain of illness narratives that echo the concerns of the risk society and take as their starting point the systematic industrial poisoning of nature, the environmental illness memoir. Environmental Illness or more narrowly, Multiple Chemical Sensitivity (MCS) is the subject of Todd Haynes film *Safe* in which a wealthy housewife from the San Fernando valley develops an increasingly troublesome range of vague symptoms which she attributes to constant exposure from the daily chemicals in her home and world. Patronized by her family physician who declares her medically fit, she ultimately retreats to an igloo-like bunker or safehouse at an alternative holistic ranch where she is increasingly shut off from contact with the natural world and other people. The film develops and maintains an ambiguity and uncertainty that often characterizes the experiences of people with environmental illnesses: is it her social *ennui,* some psychological problem or a biological vulnerability to toxins that causes her illness?

While earlier cancer and AIDS narratives, despite their protestations, relied on a belief in causality and the scientific enterprise, reflexive risk narratives are suspicious of both. Because many modern risks, ie the gene-altering effects of radiation or the effects of organophosphates on brain development, escape perception (and may not even be experienced for generations), they require qualified expert opinion, and that expert opinion is more often seen as in the pocket of one or another special interest group: a national safety advisory council that wants to keep a nuclear power plant open or an expert biochemist hired by Monsanto to assure the public of the safety of its product. As Beck writes "the sciences' monopoly on rationality is broken. There are always competing and conflicting claims, interests and viewpoints of the various agents of modernity and affected groups, which are forced together in defining risks in the sense of cause and effect, instigator and injured party. There is no expert on risk" (29).

In the *Body Toxic,* subtitled *An Environmental Memoir,* the poet Suzanne Antonetta catalogues the illnesses of her mind and body: "I have or have had one spectacular multiple pregnancy, a miscarriage, a radiation-induced tumor, a double uterus, asthma, endometriosis, growths on the liver, other medical conditions like allergies."[xiii] Against this litany, Antonetta lists the many instances of corporate and government malfeasance, ignorance and negligence that poison the natural world, particularly the environs of her childhood, along the New Jersey coast, an epicenter of multiple Superfund sites and geographical disease clusters: From DDT trucks spraying the marshes to Ciba-Geigy and Union Carbide using the area to illegally dump toxic wastes for decades, from Denzer &Schaeffer X-ray 's disposal of chemical solutions in the septic system to the Oyster Creek Nuclear Reactor's release of toxic fission material into the waters, Antonetta describes what Beck called the latent side effects of modernity. The all-pervasive riskscape is mapped onto the landscape, which is again mapped on to her body. But this is not a simple cautionary tale of cause and effect where the poisoned landscape is ingested and incorporated into the body with so many crabs and cranberries. For every time Antonetta repeats her list of symptoms, each time with a difference, she offers a different causal mechanism: the poisoning of the landscape is followed by her poisoned genetic inheritance—she describes having an autistic and depressed bajan grandfather and a manic bipolar grandmother; she blames her years of drug use, "the years that, to compensate, maybe I poisoned myself"; she blames the food she ate and water she drank; she blames radiation treatment she may have received for enlarged tonsils; and finally, she blames the medications and the ECT treatment she received for her own diagnoses of depression and bipolar disorder.

Antonetta's narrative differs in form and content from traditional illness narratives. Her text is allusive, spiraling, recursive and repetitive. There is no clear sense of progression or beginning, middle and end. There is certainly no before and after. Because risks are everywhere and always multiple, they are overdetermined—there is no clear singular cause and effect relationship and the very idea of causality is called into question, as the narrative doubles back on itself, repeating, and circling the marshes of Tom's River; illness is not offered as a disruption in a forward marching story, as it is in the cancer and AIDS narratives, because risks and their effects are always present aspects of personal identity and biography; chronology, both in story time and narrative time, are relinquished because the old story, "I was well, I got sick and I got better or I will die" cannot frame the new risk experience; the specific forms that illness takes, the "multiple pregnancies, miscarriages, benign growths or tumors, allergies" do not have the ontological or even nosological certainty or mortal imperative that illnesses like cancer and AIDS possess.

Ontological uncertainty is also a critical feature of illness experiences defined by recent advances in genetic screening. As people are found to harbor or possess genes that significantly increase their risk of developing medical conditions like ALS, coronary artery disease and ovarian cancer, a new state of experience has arisen somewhere between illness and health which has also led to a new direction in illness narratives. In May of 2013, Angelina Jolie, the American actress and celebrity, wrote an editorial for *The New York Times* discussing her choice to have a preventative or prophylactic double mastectomy.[xiv] Jolie begins her piece with a *mise en abyme:* an illness narrative within an illness narrative. Her mother "fought cancer" and died at 56 after a decade long struggle, depriving her grandchildren of a chance to know her: Jolie would not let that story be hers and so elects to have a prophylactic mastectomy. In keeping with the direct clinical language of contemporary memoirs, she describes "nipple delay", temporary fillers, drain tubes and breast expanders but also compares the scene to something out of a "science-fiction film". The decision and treatment are "empowering" and her family is brought closer together. But what makes this narrative distinct from breast cancer narratives of the prior generation is that she does not have breast cancer, she is at risk for it. Her illness narrative is a pre-narrative or the illness narrative of a previvor, a condition defined solely by risk. Jolie carries what she describes as a "faulty" gene, BRCA1 which her doctors estimate conveys an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer. The numerical certainty of 87% belies a number of uncertainties, ambiguities and complex assumptions about medical cognition and causality:

1. While her physicians probably did explain her risk of developing breast cancer as 87%, because of genetic polymorphisms, different mutations in the BRCA gene covey different risks, ranging from 65-74% in one large meta-analysis of 22 studies.[xv]
2. The American cancer society and other guideline creating bodies actually recommend screening MRI and mammography for BRCA1 carriers and Jolie's

mortality in the setting of heightened medical surveillance and treatment without prophylactic mastectomy would be assumed to be no different.[xvi]

3. The application of population based epidemiologic risk to an individual in a clinical setting is epistemologically faulty, as patients do not get 87% of a disease, they either get a disease or they do not.
4. Cancer, unlike infectious diseases, has been generally understood in terms of epidemiologic models of multiple causation, but recent developments in genetic screening, like the BRCA genes, drive a desire for the doctrine of specific etiology: genetics as destiny.
5. Finally while it is not a hundred percent certain that she will get breast cancer, it is a hundred percent certain that she is at risk for breast cancer: a technical, scientific or objective definition of risk is replaced with the subjective, lived experience of risk.

Jolie frames her mastectomy as a choice, but it a choice with a polemical and moral imperative to be healthy in a particular way: she moves easily and quickly from 87% to the absolute certainty of “reality” and decides to be “proactive” and take “action”. Any other choice would be inactive and passive. She describes her decision as a “strong choice” suggesting again that any other choice would be a weak one. She does not question or offer an alternative to breast reconstruction and she writes “It is reassuring that they [her children] see nothing that makes them uncomfortable. They can see my small scars and that’s it. Everything else is just Mommy, the same as she always was.” Contrast this with Audrey Lorde’s decision to not wear a prosthesis or have reconstruction after her breast cancer surgery more than thirty years earlier, "Th[e] emphasis upon the cosmetic after surgery reinforces this society's stereotype of women, that we are only what we appear, so this is the only aspect of our existence we need to address" (58). What Jolie's choice fails to address is that we are always at risk, but at some point that risk seems to cross a threshold and become medicalized. At what point does medicine begin? And at what risk threshold should we recommend expensive and potentially risky treatments and operations: Should we all get appendectomies at birth since we are all at risk for appendicitis? At what point will the lifetime breast cancer risk be high enough to recommend prophylactic mastectomies for all women?

Prophylactic mastectomies and the BRCA gene are also the subject of Joelle Burnette's illness memoir, *Cancer Time Bomb.* After her sister develops breast cancer at a young age, Burnett's mother convinces her to get genetic testing. She finds out that she is BRCA1 positive and is told that her risk of developing breast cancer is higher than 90%. She also experiences this genetic embodiment as a certainty and perceives her body as a ticking time bomb: "Until the day arrived when my surgeries removed these potential cancer incubators and I officially became a previvor, I would wake up every morning feeling like a cancer time bomb."[xvii] Her body and in particular her breasts are alienated as she experiences them as treacherous objects, incubators, bombs. For her, the status of previvor though is only granted after surgery and she becomes consumed with eliminating her body as risk: "We previvors have a predisposition to cancer, but live in a grey area that can't be defined by certainty. Rather, we willingly choose to remove everything that likely will create the disease in our bodies as predetermined by generations of genetic material" (100). But Burnette's diagnosis, treatment and surgeries, which took more than two years all told and inflicted a great of pain and discomfort were overshadowed by her sister's real diagnosis of cancer and her own liminal state: When she explains to the other people in her life that she is not sick or ill, despite her need for surgery, they respond with what she describes as "stolen sympathy" (187). She can never quite claim the status of a patient, and is stricken with guilt for the emotions she arouses.

And now to bring it home. A core tenant of the neoliberal self seems to be the disciplining imperative to manage risk; disease is viewed as poor risk management. As the sociologist David Harvey writes, in the neoliberal state "while personal and individual freedom in the marketplace is guaranteed, each individual is held responsible and accountable for his or her own actions and well-being."[xviii] With the privatization and deregulation of economic and political interests, responsibility for a successful and healthy life falls on the individual, as does blame when things go wrong. But in the case of MCS, or even asthma and cancer, it is often the deregulating policies of neoliberalism that allow for all kinds of nefarious corporate practices like the dumping of toxic compounds into drinking water or the use of known synthetic asthmagens as cheap construction materials, at least in part resulting in disease. What remains of choice and surveillance, if it is the deregulated and privatized world that is actively increasing our risks of disease? In his novel *Gain,* Richard Powers tells two intertwined stories. The first is the rise of a nineteenth century American soap and candle company from a family business to a juggernaut multinational chemical and pharmaceutical manufacturing corporation, Clare International at the dawn of the twenty-first century. The second is the story of Laura Bodey, a contemporary middle-aged woman who is diagnosed with ovarian cancer, which is in part attributed to an herbicide manufactured by Clare International. In this morality tale on the ills and benefits of the neoliberal state, Laura Bodey recognizes that there is no escape from the chemicals of modern life as they invade all aspects of her home, no way of diminishing the risk to zero through choice and surveillance:

> No longer her home, this place they have given her to inhabit. She cannot hike from the living room to the kitchen without passing an exhibit. Floor by Germ-Guard. Windows by Cleer-Thru. Table by Colonial-Cote. The Bodey mansion, that B-ticket, one-star museum of trade. But where else can she live?
> She vows a consumer boycott, a full spring cleaning. But the house is full of them. . . They paper her cabinets. They perch on her microwave, camp out on her stove, hang from her shower head. Clare hiding under the sink, swarming in her medicine chest, lining the shelves in the basement, parked out in the garage, piled up in the shed. Her vow is hopeless. Too many to purge them all. Every hour of her life depends on more corporations than she can count.[xix]

And when there are choices that can be made, they are not experienced as choices, but as imperatives, the moral imperative to be healthy. If women like Joelle Burnette or Angelina Jolie choose not to mitigate their risk through personal choice and choose not to take responsibility through prophylactic surgery, they face social, and possibly economic, censure.

The illness narratives of the 1970s and 80s were successful at challenging the belief that patients were to blame for their illnesses: we learned that cancer is not caused by repressed emotions and AIDS was not retribution for sexual promiscuity.

But we seem to be back where we started. Fat shaming is only the most current example and shows how the rationality of markets is actively constructed and contested. Even as obesity is medicalized and legitimated in the numerical spectrum of BMIs and epigenetics, individual consumers are advised to make the right choice in the face of misaligned corporate interests. Against the active construction of rational markets and selves, reflexive risk narratives, written from marginalized and uncertain illness positions, refute the desire to blame unfit, disorderly and undisciplined bodies, while calling into question the true possibility of mitigating risk through consumer choice.

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[xix] Powers, Richard. *Gain.* New York: Picador, 1998. 345.