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Breast Cancer and Invisibility: Why We Need Mastectomy Narratives

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invisibility that separate mastectomy survivors from greater society, other women, and each other. Shortly after finding her first tumor, Lorde asserted:

If I were to be born mute, or had maintained an oath of silence my whole life long for safety, I would still have suffered, and I would still die...where the words of women are crying to be heard, we must each of us recognize our responsibility to seek those words out, to read them and share them and examine them in their pertinence to our lives (*Cancer Journals* 21).

Lorde's willingness to air her fears, advocate for differently-chested women, and encourage others to tell their stories demonstrates what medical sociologist Arthur Frank calls the "ethics of storytelling" (*Wounded Storyteller* 17). Frank believes narratives about mastectomy, and medical stories in general, are more than mere entertainment or information. They can be a vehicle for "genesis" (*Wounded Storyteller* 72). They can also re-create a new identity out of confusion from what Frank calls the "narrative wreckage" of illness (54). The "wreckage" of illness requires stories, because it is through story that an ill body makes sense of the sudden disruption that severe illness causes (69). Eventually, as the ill person begins to integrate the experience of disease and treatment, that person may move on to become part of an oral tradition or even become an ambassador for others with similar medical difficulties.

Part of the ethics of storytelling is realizing that stories are as important for the listener as for the teller. This means it is not only helpful but imperative that ill people impart their stories and that others try and hear them. Note that Lorde implies reciprocity in "There Are No Honest Poems About Dead Women," asking, "What do we want from each other," not "What do I want just for me?" (*Collected Poems* 409).

Few tell their stories with more imperative and urgency than Lorde. In a speech to the Modern Language Association in 1978, Lorde says, "I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised and misunderstood" (*Cancer Journals*, 17). A large part of Lorde's cancer story revolves around "transforming silence into action" (21). After her mastectomy, she writes prolifically about breaking through differences to combat various societal oppressions, and she also speaks out about her refusal to hide her one-breastedness with reconstruction or prosthesis after mastectomy. Of these topics, she writes passionately in *Cancer Journals*, as well as later in life, in *Burst of Light* and various poems. I too

have my own mastectomy story, similar and different from Lorde's. Like Lorde, I had a mastectomy on the right side. We were both in our early 40s at the times of our diagnoses. Unlike Lorde, I am a white woman. I was not eligible for reconstruction, due to a piece of chest wall also being taken in surgery. And while Lorde and I both identify as lesbian, unlike Lorde, I had my mastectomy after marriage equality's legality, where I was permitted to name my female spouse as my next-of-kin at the hospital.

A main reason mastectomy patients need stories is because we stand ensconced behind reconstructive implants, prostheses, or at the very least, shame and confusion. Like Lorde, I believe mastectomized women should have freedom in choosing whether reconstruction, prosthesis, or remaining flat and scarred is right for them. For instance, Lorde says, "The emphasis upon wearing a prosthesis is a way of avoiding having women come to terms with their own pain and loss" (*Cancer Journals* 49). I argue that there is a difference between breast cancer in general and mastectomy in particular. Unlike breast cancer, signified by pink ribbons, large hospital wings, and major corporate fundraisers, mastectomy sometimes feels like breast cancer's hidden taboo, its dirty little secret, a subset of breast cancer treatment that amputates and mutilates. As a speaker in Lana Lin's film *Cancer Journals Revisited* says, "When I first went flat, it was very confusing to me. The flat female body is not currently known."

This is not to imply that breast cancer patients who do not require mastectomy need less support or have fewer stories to tell; it also does not imply that storytelling only serves people with mastectomy or illness in general. However, storytelling -- and its absences -- can specifically heal or hinder the lives of mastectomy patients.

One reason mastectomy stories are important is because of what Alice Walker, in *In Search of Our Mothers' Gardens*, refers to as the "importance of models" (3). Lorde echoes Walker, who writes about her early lack of knowing writers and artists of color, by stating, "As a 44 year old Black Lesbian Feminist, I knew there were very few role models around for me." (*Cancer Journals*, page 57). The need for seeing oneself reflected back through others, to know others may exist who have already encountered a similar experience, is a fundamental need, according to both Walker and Lorde. Lorde, referring to her other marginalized selves, such as Black and lesbian, declares after becoming one-breasted, "How am I supposed to do this now?" (*Cancer Journals* 57). She did not know many Black and lesbian poets who also happened to undergo mastectomy.

I am a white woman, lesbian too, sometimes a poet, always looking for teachers and role models. Like Lorde, I find that telling my story and refusing an "oath of silence" hones my desire to merge my own marginalized identities with my work. To be clear, I cannot speak from the

black perspective. I also do not equate the challenges of mastectomy with oppressions of People of Color. I do believe one's work should be from a place of lived experience, and so my desire to merge my mastectomy story with other aspects of life inspires me toward my own action. For instance, I use my counseling work to advocate for women who have cancer, have been raped, molested, beaten by partners, lost children, attempted suicide, and a host of other traumas. No two clients' stories are the same, nor does mine duplicate theirs. But my work since mastectomy has a different urgency to it than prior to mastectomy. It's one more source of vulnerability from which I can understand others.

Another reason I find openness about mastectomy meaningful is that there is significant overlap between mastectomy and studies of gender. Lana Lin, filmmaker of 2019's *Cancer Journals Revisited*, candidly tells her film's viewers, "I...assumed I was not at risk of breast cancer because I scarcely had breasts, and did not identify myself with them." Another speaker in the film, who identified as male prior to breast cancer diagnosis, reports that their estrogen-receptor-positive breast cancer challenged their views of gender as static. They indicate, "I don't identify myself as a woman but when I got sick something happened with that" (*Cancer Journals Revisited*). In my own writing, I said in 2017 that I still felt like "half the woman I used to be," two years after my surgery. Though I still identify as cis-gendered, I wrote about my fears of my femaleness due to cancer: "I cannot wage a war against a piece of me without waging war against all of me. I cannot care about my remaining breast, because I've convinced myself that my breasts are dangerous; the right one is gone, and the left one is Cancer Potential" (May 2017).

Despite the anger and loss, it is important to persist and find new connections and meaning. For me, I began studying mastectomy academically, further investigating how mastectomy presents a unique inroad into discussions about gender. Mastectomy skews traditional views of gender normativity that say women have two breasts. Therefore, mastectomy is already prime ground for discussions of non-normativity. Judith Butler, in *Bodies That Matter*, iterates that "the normative force of performativity--its power to establish what qualifies as 'being'--works not only through reiteration, but through exclusion as well. And in the case of signification, those exclusions haunt signification as its abject borders or as that which is strictly foreclosed: the unlivable, the nonnarrativizable..." (140). Mastectomy, as a construct not performed by most people, allows us the chance to view the "abject borders" beyond gender norms and delve into the gray areas that blur the lines between male and female. Therefore, I see it as imperative that I be transparent about my mastectomy, such that mastectomized people can become more "signifiable" and "narratizable." I

want us to count as human, our bodies to not be excluded as exceptional or “other.”

Sometimes this means educating future generations, which is another benefit of mastectomy writings. Family history gets passed on by patients. Eighteenth and 19th-century novelist Frances “Fanny” Burney mails her mastectomy details to her sister Esther; Burney and her husband later emend the letters to make them more literary (Epstein 139). In case she never got to see Esther again (with Fanny living in France, during the Napoleonic Wars, and Esther in England), Burney notates her mastectomy in very specific detail, warning Esther that she may or may not survive. (She did in fact survive until age 87) (*Encyclopedia Britannica*).

A third function of mastectomy stories is passing on a history of medicine. Burney, when informing her sisters of her mastectomy, may or may not have thought her letters would be textual artifacts, studied in the 20th century and beyond. But Burney’s writings live long beyond her, educating current patients and scholars about the mastectomy process. Helle Mathiasen, a medical humanities scholar who studies Burney’s 1811 surgery, records, “Seven men in black enter her room. One doctor demands two old mattresses...She mounts the bed; they spread a cambric handkerchief over her eyes, but she sees ‘the glitter of polished Steel’” (“Mastectomy Without Anesthesia”).

Lorde’s accounts give readers a more recent, and just as detailed, record of what mastectomy is like. Lorde recounts not being able to move her right shoulder after her surgery. “Wrapped around (her) chest was a wide Ace bandage under which on (her) left side the mound of (her) left breast arose, and from which on the right side protruded the ends of white surgical bandages” (*Cancer Journals* 36). As I read Lorde’s account, little seems to have changed in 2015, when I had my mastectomy. I remember the Ace bandage and the inability to move my right shoulder. One difference is that Lorde came home on the fifth day after surgery (40); doctors sent me home after only one night under hospital surveillance.

Before I went home, a social worker gave me pamphlets about where I could buy a prosthesis. Like Lorde, I got more information about prostheses than how to care for my wound at home. Lorde objects, “Breast prostheses are offered to women after surgery in much the same way candy is offered to babies after injection” (65). She continues to say that prostheses are more for others than for the patient: “The real truth is that certain other people feel better with (a prosthetic breast) stuck into my bra, because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference” (65). Lorde’s story offers medical personnel a glimpse into the patient experience. Thus, Lorde illustrates

another benefit to mastectomy stories: They teach doctors, nurses, techs, and insurance companies how to make healthcare better.

Anne Boyer's work in *The Undying* attempts to reach patients and healthcare professionals alike. She makes statements such as, "I was drugged and no one explained what they did to me" (112) and, regarding inequity in healthcare, she says that female cancers "eradicate" women, especially those of marginalized class, race, and ability status (118). Like Lorde, Boyer's nonfiction sounds much like what I call Reformation narrative, in that she cannot separate herself from the cancer in her own body and the social inequities that further wound it. She does not extract the physical facts of healthcare (bandages, scars) from the larger issues of inequality when educating her audience about what needs to change.

Commemoration is yet another aspect of mastectomy narrative. Lorde names Eudora, one of her first lovers, who died of breast cancer in her 40s. "I carry tattooed upon my heart a list of women who did not survive," Lorde writes (*Cancer Journals* 40). She adds that she has one space left for another name, her own (40). Honoring the dead is yet one more way Lorde and I share commonality in our cancer writings. In addition to my grandmother and aunt, I consider Lorde one of the dead from cancer who inspires me to care for myself and others and do whatever work I can, in whatever capacity I can, to honor the memory of those who the disease has already claimed. In a 2018 poem, citing my Western Pennsylvania roots, I write:

Death comes early
for the women in this family
of rust belt capillaries
cancerous dangerous tributaries
the cells of the Allegheny
gush into the Monongahela, malignantly /
to form the Ohio
and me, mightily

In another, I say,

One birthday
I gave away a breast
a gift to myself
so I might outlive my grandmothers
or at least add one more year

My mastectomy scar reminds me I am part of a legacy of strong women, relatives and unrelated women alike, a community of those who have gone before. Lorde too relates much of her strength to her extended “family of women;” for Lorde, the names include “Blanche and Clare and Michelle and Adrienne and Yolanda and Yvonne and Bernice and Deanna and Barbara and Beverly and Millie,” women who are “macro members in the life dance” and “micro members from within” (*Cancer Journals* 47).

I’ve addressed mostly how mastectomy narratives benefit others, but these narratives exist for the self as well. From reading Lorde, Burney, and others, I’ve determined that writing or telling one’s mastectomy story helps patients in the following ways: To unsilence oneself and have power over feelings of powerlessness; distance from the mastectomy event; create memory of what happened; express grief or trauma; and grow into a newer self or identity.

Lorde speaks much about the link between silence and powerlessness. For instance, she states, “The terror and silent loneliness of women attempting to replace the ghost of a breast leads to yet another victimization” (*Cancer Journals* 68). Julia Epstein says of Burney that Burney’s letters “exteriorize the self’s story” to result in “a therapeutic and healing process” (162). One reason both Lorde and Burney unsilence themselves is to gain power or control; Epstein points to the healing benefits of “giving (as opposed to taking) a history” and describes it as “cathartic” for Burney (152). Lorde’s entire essay “The Transformation of Silence Into Action” has this notion at its core. So does much of *Cancer Journals’* introduction, such as “I do not wish my anger and pain and fear about cancer to fossilize into yet another silence, nor to rob me of whatever strength can lie at the core of this experience” (*Cancer Journals* 7).

Transmuting emotions from inner thoughts into outside narrative also allows the patient to create some distance between self and illness. Epstein says Burney wrote to “detach and obscure the covert narrative,” one of violence toward her body (154). Lorde rarely, though occasionally attempts to distance herself; when she does, her writing lacks the introspection she usually possesses. For instance, she describes her disease in the third person and objectifies it when she journals in 1978, “So this fall I met cancer” (*Cancer Journals* 25).

Paradoxically, patients want to distance themselves yet also remember. Sometimes memory comes only once words spill out. Once I started writing about my surgery, I remembered the pain medicine making me vomit; the orderly who said he had cancer too; and the doctor telling me she planned to “throw the kitchen sink at me,” chemo-wise. Lorde also writes vivid memories: “The gong in my brain of ‘malignant,’ ‘malignant,’

and the icy sensations of that frigid room, cut through the remnants of anesthesia...I yelled and screamed and complained for extra blankets, but none came” (26-27).

Memory can also heal grief. Mastectomy causes loss, which narrative can help express. Lorde originally felt a great well of grief after her mastectomy. She felt a “mourning for (her) breast” (78) but was eventually able to write her way into a new understanding. This new perspective was that, despite originally saying she would “give anything to have done it differently” and not lose a breast (78), she changed to say, “I would never have chosen this path, but I am very glad to be who I am, here” (79). She wrote these words approximately six months after her mastectomy. This illustrates the power Lorde found in writing her story and the transformation that can occur by facing fears, rather than “silencing” them (18).

Part of the grief after mastectomy springs from not just loss of breast, but loss of self. The identity confusion sometimes caused Lorde to air feelings of depression: “I think I was fighting the devil of despair within myself for my own soul” (79). In my own writing, I refer to a line drawn down my middle, with my old self inhabiting the side with my remaining breast, and an unknown person on the right. Two years post-amputation, I wrote, “Ever since the surgery, half of me—the nurturing half, the artistic half, the fun half--has never truly woken again.” Now, seven years later, I rarely feel “split” inside. I attribute some of the identity integration to time, some to therapy, and most of it to reconnection with loved ones and interests, including writing.

“Any amputation is a physical and psychic reality that must be integrated into a new sense of self,” Lorde iterates (14). While tales of integration are desirable and useful stories to tell, many patients never feel integrated. In this situation, I recommend that people be allowed to be where they are, without being rushed to tell more comforting narratives that allay loved ones’ fears. Illness can be hard to hear about, especially for the health-privileged, or those who have never suffered serious illness. Rather than hide illness for the sake of making healthy people comfortable, I endorse Lorde’s approach, which is “acceptance of difference as part of our lives” (68) and refusing silence around one’s depression, identity confusion, or other fallout from grave illness.

However, sometimes people feel well and are afraid of becoming healthy, in case they lose their health again. They may also not know how to move beyond fear, anger, and grief, because no one has taught or inspired them. In this way, mastectomy narrative can be very much again for others as well as for the self. Mastectomy narrative can generate hope where there feels like none exists, which ultimately can mean the

difference between feeling like one is surviving or not. For instance, Lorde served as an ambassador of hope for me. I, in turn, find it healing to share my story with others.

This is not the same as false hope or forced happiness. “Looking on the bright side” for the sake of it, not because of genuine wellbeing, is a sentiment often encouraged in cancer patients, especially women (76). What instead helped me were patients, including Lorde, who embraced a dialectic, the ability to hold pain and hope in the same hand. What helped were words of wisdom like “Breast cancer, with its mortal awareness and the amputation which it entails, can still be a gateway, however cruelly won, into the tapping and expansion of (our) own power and knowing” (54).

We must continue to live, whether trapped by the shame of unspeakability or moved to use our cancers for political action. Boyer mentions a terminally ill patient who chose to forgo chemotherapy and risk earlier death, rather than be guilted into more treatment by doctors and family. Boyer urges, “Live. Refusal can be isolating; the social enforcement of medical compliance around a gendered disease like cancer, brutal” (196). I too believe that living, in itself, can be its own form of healing. “We must learn to count the living with that same particular attention with which we number the dead,” Lorde asserts (*Cancer Journals* 54). Six years ago, doctors said my refusal of radiation treatment cut my odds of living another five years in half. My refusal to finish all my chemotherapy treatments, due to intolerance of side effects, caused my oncologist to chastise me and say I cut my odds of living five years even more. Another oncologist asked me to consider having my ovaries removed due to personal and family history of cancer, and when I asked if he advised males with cancer history to remove their testicles, he averted my question. Ultimately, while I hope to live longer than my grandmothers, who both died in their mid-50s, I was happy to turn 50, because for a while I didn’t think I’d make it past 43. My overall sentiment about longevity can be summarized in a quote by Lorde: “I want to live the rest of my life, however long or short, with as much sweetness as I can decently manage, loving all the people I love, and doing as much as I can of the work I still have to do” (“Burst of Light” 76).

There is much work left to do, with part of that “work” being setting limits, caring deeply for myself, and living the unspectacular everyday elements of life. Acts of self-care can “be an act of political warfare,” as Lorde proclaims (131). There is revolution in the ordinary, in scars and disease, in wellness, in the here and now, and in stories. If there is any wisdom I myself can impart, it is this.

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