THE TRANSFORMATION OF SILENCE INTO STORYTELLING: AN ANALYSIS OF MEANING AND STRUCTURE IN NARRATIVES ABOUT MASTECTOMY

DANA M. GRANDE

Bachelor of Arts in English
The College of Wooster
May 1993

Master of Science in Education in Counseling
Youngstown State University
December 1997

Submitted in partial fulfillment of the requirements for the degree
MASTER OF ARTS IN ENGLISH
at the
CLEVELAND STATE UNIVERSITY
December 2021

We hereby approve this thesis for

DANA M. GRANDE

for the Department of English

and the CLEVELAND STATE UNIVERSITY'S

College of Graduate Studies by

Committee Chairperson, Dr. Adrienne Gosselin

Department & Date

Committee Member, Dr. Julie Burrell

Department & Date

Committee Member, Hilary Plum

Department & Date

Student's Date of Defense: December 8, 2021

THE TRANSFORMATION OF SILENCE INTO STORYTELLING: AN ANALYSIS OF MEANING AND STRUCTURE IN NARRATIVES ABOUT MASTECTOMY

DANA M. GRANDE

ABSTRACT

With more people receiving a breast cancer diagnosis, more patients look to stories and literature for models of themselves. They seek catharsis, new identities, ways to grieve, find camaraderie with other patients, and connect themselves to the larger world. Sometimes they read the works of others, such as Audre Lorde, to feel less isolated. At other times, they tell or write their own stories as a way to educate, connect, commemorate, or express. Some patients, such as Lorde and the author, find it difficult to separate their cancers from societal problems at-large. The following thesis looks at how and why mastectomy stories are needed. It also shows how traditional theories of illness narrative fall short of representing many mastectomy patients' experiences. Additionally, the thesis illustrates how pink ribbons, ubiquitous symbols of breast cancer marketing, simultaneously create and suppress dialogue about the unique struggles of living in a mastectomized body.

TABLE OF CONTENTS

Page

ABSTRACT iii

CHAPTER

I. INTRODUCTION 1

II. BREAST CANCER, MASTECTOMY, AND UNSPEAKABILITY 7

III. WHY WE NEED MASTECTOMY STORIES 15

IV. FROM SILENCE TO SPEAKING 28

V. FROM SPEAKING TO LIVING 44

VI. BLACK-AND-BLUE AND PINK 54

VII. CONCLUSION AND FUTURE IMPLICATIONS 62

WORKS CITED 65

CHAPTER I

INTRODUCTION

What do we want from each other

After we have told our stories

Do we want

To be healed   do we want

Mossy quiet stealing over our scars

--Excerpt from "There Are No Honest Poems About Dead

Women" by Audre Lorde

Black-lesbian-poet-mother-warrior Audre Lorde asks us to consider why we tell stories: We tell them to heal, speak out, survive, or perhaps instead to be heard and fade into "mossy quiet" (*Collected Poems* 409). "There Are No Honest Poems about Dead Women" refers to mastectomy scars, and Lorde narrates from personal experience. Lorde had her right breast removed in 1978, after a breast cancer diagnosis. When doctors told me I had stage III breast cancer, I failed to respond to initial chemotherapy, then had an emergency life-saving mastectomy on my birthday in 2015. More than any aspect of recovery that's helped me, Lorde's poems, others' stories, and my own writing have expedited my healing. The sharing of personal cancer stories, both with patients and non-patients alike, orally and on paper, are critical to recovery. According to Walter Benjamin, storytelling, whether in the form of spoken word, prose, or poetry, serves multiple functions in society: to transmit information, entertain, give advice, navigate hardship, and commemorate, among other reasons. In "The Storyteller," Benjamin states the need for story, not just in the form of novels, which he says isolates the teller from the reader, but also he calls for stories in spoken language or personal language. He warns against the loss of personal transmission of real-life experiences and "counsel," meaning firsthand "wisdom" (*Illuminations*).

Medical sociologist Arthur 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). Frank describes the "communicative body," or an ill person who transmits knowledge about one's illness to other people (49). A communicative body carries the ability to salvage the "wreckage" of grave illness (69). 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.

Illness stories are an important notion for the teller as well as the listener. Both Lorde and Frank pose the concept of storytelling "ethics." This means it is not only helpful but imperative that ill people impart their stories and that others listen. 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). She adds, “And where the words of women are crying to be heard, we must each of us accept our responsibility to seek those words out, to read them and share them and examine them in their pertinence to our lives” (21). Here Lorde implies that by keeping our stories to ourselves, society is denied an important lesson. Lorde implores us to take action toward communicating our truths, because doing so is an imperative, a “responsibility.”

A large part of Lorde’s cancer story revolves around “transforming silence into action” (*Cancer Journals* 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.

The following paper uses text of mastectomy survivors, especially Lorde's 1980 *Cancer Journals* and her 1986 *Burst of Light*, to show how women with mastectomy talk about their experiences and connect them to larger, systemic concerns. I use Frank's theories of illness narrative in *The Wounded Storyteller* (2013) as a structural background for understanding narrative concepts. I also utilize narratives from Fanny Burney (1811) and Anne Boyer (2020) to show that despite centuries in-between certain narratives, they all serve similar purposes and meet certain needs. Furthermore, I inject my own written creative nonfiction and poetry into the paper as an autoethnographic approach to illustrating the healing nature of mastectomy narrative.

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 Revisite*d 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, the scope of this paper, and the analysis of storytelling theories that follow, deal mainly with how storytelling -- and its absences -- can specifically heal or hinder the lives of mastectomy patients.

Also note that, though mastectomy simply means breast removal, for the purposes of this paper, "mastectomy" and its coinciding terms "mastectomy stories" or "mastectomy narrative" here mean those works written by and about women who had mastectomy due to cancer and not as part of gender transition surgery, other medical conditions, injuries/accidents, or other reasons. This does not mean these experiences also don't deserve recognition. Related experiences such as breast cancer not requiring surgery, cancer treated by lumpectomy (tumor but not breast removal), plus the stories of men in the breast cancer movement, which also are worthy of literary study, are likewise too broad for the parameters of the discussion that follows. Rather, for the scope of this project, mastectomy after breast cancer is the primary focus.

Chapter II offers historical contextualization of mastectomy, including information about famous writers who have had mastectomy. It also encompasses the medicalization of the breast, various breast myths, and how feminist studies interplay with mastectomy literature. This sets the reader up for discussion of the silences surrounding mastectomy and the corresponding need for mastectomy storytelling.

Chapter III outlines the myriad reasons why mastectomy stories heal both the teller and the listener. I explain several scenarios in which mastectomy narrative serves health. Chapter IV introduces seven types of illness structures. Frank proposes three, which are "Chaos Narrative," "Restitution Narrative," and "Quest Narrative;" I see an additional four, which I label “Pre-Integration,” “Integration,” “Maintenance,” and “Reformation” Narratives. I attend to the importance of “non-speech” and incubated silence as well. In Chapter V, I extend my work of the prior section by further exploring Maintenance and Reformation Narratives. I pay particular attention to Reformation Narrative as a vehicle for addressing social illness alongside personal illness. Finally, in Chapter VI, I explore the pros and cons of pink ribbon campaigns and their impact on communication about mastectomy. My conclusion, Chapter VII, ties this together with previous topics, before illuminating future implications for my work.

To accomplish my aims, the following thesis uses an autoethnographic approach. Sarah Walls defines autoethnography as employing “highly personalized accounts that draw upon the experience of the author/researcher” and “lets you use yourself to get to culture” (146-147). By using my own experiences as a mastectomy patient, I intend to bring the micro/personal to a more macro/widespread level. As such, this makes for a reflexive project, one that uses my own mastectomy story to tell a much larger story. This project is not just a research project that draws upon positivism or strictly traditional forms of academic discourse. It is also personal. My hope is that it comes full-circle, folding in on itself, helping you understand the mastectomy narratives of others by telling you my own.

CHAPTER II

BREAST CANCER, MASTECTOMY, AND UNSPEAKABILITY

I barely glance at you
as if my look could scald you
though I'm the one who loved you

I want to touch my fingers
to where your breasts had been
but we never did such things
--Excerpt from "A Woman Dead in Her Forties" by Adrienne Rich

In "A Woman Dead in Her Forties," Adrienne Rich boldly describes her love affair with a woman whose breasts have been amputated. I say "boldly" because, even though Rich says she "wants to touch her fingers" to her lover's scars but doesn't do it, she at least writes of desiring to. Few poets, at the height of Rich's fame in the 1970s, wrote lesbian verse, and this poem combines the social taboo of same-sex love with the unspeakability of cancer and breast loss.

To understand why it is difficult to talk or write about mastectomy, it first is helpful to understand a social and historical context for cancer and breast surgery. From a language perspective, almost all representations in English refer to breasts in the plural. There are tatas, jugs, tits, bazoombas, knockers, and boobs, with the pair as the default. Pictorial representations of women almost universally show two breasts, not one or none. Bathing suits and bras have two cups. Additionally, a mastectomy involves nipple and areola loss as well as complete removal of breast tissue, including that under the armpit and usually several attached lymph nodes. The result leaves either flatness or, in my case, a bony indentation that looks like a shallow canyon ravine with a scraggly pink and purple scar channeling through it.

Mastectomy has a way of “othering,” or causing a feeling of difference. One reason is due to gender norms about the body and a societal linkage of breasts to maternity, womanliness, and sexuality. Queer studies scholar Eve Sedgewick, who maintained a gender fluidity until she had a mastectomy, quipped, “Shit, now I guess I really must be a woman” (Boyer 8). The breast and sexuality intricately intertwine; mastectomy, as a removal of breasts, both perverts and subverts the idea of a womanly ideal. Frances “Fanny” Burney scholar Julia Epstein observes, “The breast emblematizes both privacy and sexuality, and breast cancer, by intruding on the radical privacy of the body and thus medicalizing sexuality, threatens and breaks down that emblematization” (155).

As sexuality and shame often intertwine, some women choose to not disclose at all that they have lost a breast. George Ballard, biographer for 18th-century feminist Mary Astell, reports that Astell had a mastectomy before her death from cancer in 1731.

She “dressed and managed (her breast) herself,” and when it came time for it to be removed, she asked her surgeon to “take it off in the most private manner imaginable: and would hardly allow him to have persons whom necessity required to be at the operation” (Epstein 155).

In addition to being symbols of sexuality, fertility, and femininity, women’s breasts are “symbols of morality,” according to Epstein (155). As such, they are fetishized yet simultaneously kept hidden due to their “sexual power,” as evidenced by the 1678 treatise, *A Just and Seasonable Reprehension of Naked Breasts and Shoulders* (155). Another treatise, concerned about how breastfeeding makes breasts publicly shown, also warns women not to show any “pleasure while breastfeeding” (155). I interpret these treatises to mean the breast symbolizes privacy but also is subject to public admiration, as long as not too much is shown. I would add that there are several examples of the paradoxical fetishization and secrecy of breasts in our society; one is the restaurant chain Hooters, where women show much, but not all of their breasts, as a sales gimmick for mostly male heterosexual clientele.

With breasts being a source of public adulation, it stands to reason that losing a breast may mean losing that adulation. Lady Delacour, a character in Maria Edgeworth’s 1801 novel *Belinda*, contracts breast cancer and fears losing her attractiveness. Delacour refuses to see a doctor and emphatically protests against any surgery: “I would not for the universe have my situation known...Why my dear, if I lose admiration, what have I left?” (154-155). I suggest that mastectomy induces much fear not only because it is a painful procedure, but also because many women’s sense of legitimacy lies in beauty. Additionally, I agree with Lorde that society has difficulty acknowledging any form of women’s chests other than the proportioned pair. On the topic of prostheses and reconstructive surgery, Lorde emphasizes, “I refuse to hide my body just because it might make a woman-phobic world more comfortable” (*Cancer Journals* 62). I go one step further and claim that breast cancer is the most popularized and known cancer, with the most fundraising and corporate funding, because men, more so than women, need women’s chests to be an intact, symmetrical, unscarred pair. I suggest that other breast types fly in the face of public norms, and breast cancer threatens men’s idealization of what a desirable female torso looks like. I add that breast cancer sells more t-shirts and swag than other cancers, because livers aren’t sexy and lungs aren’t considered “hot.”

Another reason mastectomy survivors keep their statuses hidden is because cancer connatates death. Lorde warns, “Post-mastectomy women must be vigilantly aware that...we are the most likely of all women to develop cancer somewhere else in the body” (75). My scar reminds me daily of a brush with mortality. Anne Boyer quotes S. Lochlann Jain, who writes, “one charming little diagnosis threatens to suck you under, into the archetypal death doled out by the feminine body” (8). Though not necessarily an immediate death sentence for all, a significant portion of mastectomy’s unspeakability comes from breast cancer’s mortality rate. Mastectomy feels like a mark, if not of death then of death potential. In the United States, breast cancer claims 40,000 lives per year (DeShazer 2). Women who did eventually die of their breast cancers include Lorde, Sedgewick, Susan Sontag, Kathy Acker, Alice James, Abigail Adams Smith, and Rachel Carson (Boyer 2-8).

Documentation of breast diseases threatening women’s lives goes back thousands of years. Mukherjee writes that breast tumors appeared as early as 2500 B.C., in an

Egyptian document where the physician Imhotep wrote that certain breast tumors were "large, spreading, and hard; touching them is like touching a ball of wrappings, or they may be compared to the unripe hemat fruit, which is hard and cool to the touch" (40). In approximately 550 B.C, Herodotus, husband of Queen Atossa of Persia, wrote that Atossa quarantined herself away and would permit no doctor to examine her bleeding breast tumor, until she was in such pain that she allowed a Greek slave to sever the whole breast with a knife (41). Though it cannot be confirmed whether or not very old cases of breast tumor were in fact true cancers or a more benign malady, people have nonetheless documented similar constellations of symptoms for a very long time, often with much foreboding (Imhotep proclaiming that certain breast tumors had no cure) and shame (Atossa hiding herself in her room and keeping her afflicted breast swathed in cloths) (41).

The English word "cancer" comes from the Greek "karkinos," or "crab," due to Greek physicians of Hippocrates' time (400 BC) noting that certain tumors choked surrounding blood supply by growing leg-like spindles (47). In English, the word "crab" denotes much less fear than "cancer." Interestingly, the word "oncology," an English term associated with cancer treatment, comes from the Greek word "onkos," meaning mass, load, or burden (47). While Hippocrates and his colleagues mainly dealt with surface tumors, such as breast, throat, and mouth, for instance, and called most types of fleshy masses "cancer," the word has nonetheless usually meant a foreboding malady, an affliction inducing fear, even horror or terror. Additionally, due to the changes in physical appearance and potential disfigurement cancer incurs, the term is often associated with embarrassment or social isolation, such as what Atossa and other cancered people, including myself, have felt.

This is not to say that other illnesses also don't cause isolation or shame. Nor is it to infer that other illnesses often don't have the same mortality concerns, cost of healthcare, or worries from family/caretakers. For example, heart disease is still the number one killer of women. However, with mastectomy, there is societally-sanctioned shame, deep taboo, or even a sufferer's belief that a severed breast makes her a non-person. Some trauma theorists, such as Cathy Caruth, refer to trauma as a "forgetting," "not locatable," and as an "unassimilated" event (Baelev 5). Yet I contend it is more than this. I suggest that trauma is sometimes too big for memory, too big for story, and that it is so locatable it can be seen daily, for instance, in the mastectomy scar, or smelled in the odor of rubbing alcohol. If it is unassimilated, it is just as likely to cause a rearranging of bodily sense as mental function. As Boyer says, "Everything about being sick is written in our bodies first and sometimes written in notebooks later" (43).

The "notebooks" are needed to tell stories for people who don't yet have stories or who "don't know anything about having cancer...but know something about how to avoid telling a story," Boyer jokes (43). One reason, besides trauma, that breast cancer and mastectomy can feel so unspeakable is because certain cultures, past and present, frown upon mentioning cancer or breasts. This could be to save a family member from worry, as in Fanny Burney's case when she wrote to her sister Esther about her mastectomy in 1811-1812 but forbade Esther from telling their father ("Breast Cancer in 1811"). It could also be because, as is believed in some Black communities, to speak of cancer is to "claim" it and therefore attract it; or because in some Native American families, to speak of cancer is to cause it; or because in some Arab belief systems, cancer is a punishment and therefore not a topic willingly disclosed (“Cancer Screening Among Racial/Ethnic Minority Women”).

When someone has no words, or it is against moral grain to talk about mastectomy, these experiences should be respected. But for those to whom these designations do not apply, the “unspeakable” can be an opportunity for learning or growth. As Barry Stampfl says, “Recourse to the unspeakable may make up an important way station in the course of an ongoing cognitive/affective process leading to the reintegration of the traumatic event”(21). Stampfl also speaks up for the body, when it is forgotten in processes of shame or taboo. He asserts, “The role of the body is minimized when the unspeakable turns its searchlight on the question of what can or cannot be expressed, a redirection of attention that effects an unintended sublimation, causing the physical to retreat to the background” (19). It is particularly this kind of unspeakability or “sublimation” that mastectomy patients feel. On one hand, many patients prefer to forget the body, but on the other hand, they very much want to own it, integrate it. Lorde argues against sublimation and unspeakability when she advises, “The social and economic discrimination practiced against women who have breast cancer is not diminished by pretending that mastectomies do not exist” (*Cancer Journals* 68).

Lorde is correct that silence around mastectomy perpetuates discrimination. Her fortitude in fighting on behalf of mastectomized women expands through her and beyond her, influencing people like me in 2021. However, Lorde primarily focuses on direct political action, whereas my work centers mostly on narrative theory, who tells mastectomy stories, in what contexts, and how they are told. The next section breaks the topic of mastectomy stories down further, into specific reasons why these stories can and should be told, as well as who they most benefit. Ultimately, both Lorde and I speak about how silence sabotages the health of individuals, communities, and the world at large. As will be seen, the study of mastectomy stories complements Lorde’s work in that we both aim toward bringing the invisible into the light and the unspeakable onto the page.

CHAPTER III

WHY WE NEED MASTECTOMY STORIES

"Surrounded by other women day by day, all of whom appear to have two breasts, it is very difficult sometimes to remember that I AM NOT ALONE." (Audre Lorde, *Cancer Journals*, page 63).

My margin notes in *Cancer Journals* are chock-full of "I agree," "Yes!" and "I felt this way too." The book transformed me when I read it in 2018, because I'd never seen so much of my post-cancered self reflected back to me before. I needed this book. If I had never read it, I wonder whether I'd have reached the level of acceptance and desire for advocacy that I have now. Lorde represents an extremely important voice for people with breast cancer, especially those with mastectomy, because she not only openly describes her cancer diagnosis and breast amputation, but she also speaks out against the silence that separates mastectomy survivors from greater society, other women, and each other. Shortly after finding her first tumor, she 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 Frank calls the "ethics of storytelling" (*Wounded Storyteller* 17). He reminds us that "Storytelling is for an other just as much as it is for oneself" (17). In the above passage, Lorde uses the word "responsibility," implying a moral obligation to find, learn, and "share," not just listen. She also says "examine," not "observe," "see," or "take in" other women's words, suggesting that we also study and reflect on others' lived experiences.

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. For example, I’ve never overdosed from heroin, had a miscarriage, or experienced a house fire, but mastectomy helps me be present to others in a way I hadn’t before. My white privilege means I don’t know what it’s like to fear the police if I get pulled over. But mastectomy helps me listen, learn, and be more open to acknowledging differences while working side-by-side with people’s similarities.

Lorde proclaims, “In the transformation of silence into language and action, it is vitally necessary for each one of us to establish or examine her function in that transformation, and to recognize her role as vital within that transformation” (21). Therefore, it is my belief that just as silence around other forms of difference counteracts progress, so does hiding parts of oneself like mastectomy. Personally, the “transformation of silence into language and action" means transforming silence into writing, storytelling, counseling, and other forms of day-to-day action, as a critical form of advocacy.

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 left one is Cancer Potential; it is the evil twin of the one who betrayed me" (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." Butler asks, "How might the excluded return, not as psychosis or the figure of the psychotic within politics, but as that which has been rendered mute, foreclosed from the domain of political signification?" (141). The answer is to not be silent, to overcome fear and "teach by living and speaking those truths which we believe and know beyond understanding" (Lorde, *Cancer Journals* 21).

Sometimes this means educating future generations. Family history gets passed on by patients. 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 tells her how much she wishes she could be with Esther and their other sister during the surgery: "How did I think of her--how did I long--long for my Esther--my Charlotte!--" ("Breast Cancer in 1811").

A third function of mastectomy stories is passing on a history of medicine. 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"). Another 1811 account, that of John Adams' oldest child Abigail, reads, "The operation lasted 25 minutes. They dressed her wound for an hour. Although suffering agonies, the patient displayed exceptional fortitude. But just two years later, an emaciated Abigail Adams Smith returned to Quincy to die, assisted only by opium" ("Mastectomy Without Anesthesia").

Lorde's account of mastectomy in the late 1970s 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. 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.

My family and I felt anger and fear when returning home after such a short hospital stay. The insurance refused to pay for more than one night. Costs eventually totaled over $100,000. Like Lorde, I was given 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.

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 later refer to as 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. Burney lived to age 87 (*Encyclopedia Brittanica*), but breast cancer takes the lives of many younger women. 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). 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, six 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 Integration Narrative, my term for a narrative that enables tellers to make a whole out of parts, is a desirable type of story 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). We must each decide which treatment, and how much of it, is right for us, and I 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 will be 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, and in the here and now. If there is any wisdom I myself can impart, it is this.

Ultimately however, each person who loses a breast or breasts has her own route toward making sense of cancer. Indeed, just living life each day, sometimes only surviving, can be a win, but not everyone views recovery this way. Illness sometimes flows circuitously toward health, sometimes not, and each phase of talking (or not knowing how to talk) about mastectomy has its own purpose. The following section investigates the function of mastectomy stories at each step of the healing process, starting with what it's like to have no words at all.

CHAPTER IV

FROM SILENCE TO SPEAKING

> “My silence had not protected me. Your silence will not protect you.”
>
> --From “Your Silence Will Not Protect You” by Audre Lorde

Lorde refers to silence that comes from fear of conflict, shame, and death. She realized she would die regardless of whether she ever spoke her truth, warning that death “is the final silence” (*Cancer Journals* 18). Eventual mortality, brought closer to her awareness due to a breast tumor, fueled Lorde’s desire to face pain, isolation, and animosity. She equated silence with powerlessness; it had never protected her from her fears.

I concur that silence ultimately creates barriers to communication. However, I divert from Lorde by suggesting that sometimes silence is a necessary part of illness, especially in the beginning. This is because not all people have the skills, energy, or support to unsilence themselves. It is also because silence can allow for an incubation or hibernation period, a chance to look inward and assess one’s needs before engaging with the world. Moreover, illness occurs so deeply in the body that it can exist beneath words, such that language and the ailment or injury don't cross each other's paths. In "On Being Ill," Virginia Woolf speaks about the confusion and lack of words that even a flu can cause. Woolf says:

> English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache. The merest schoolgirl, when she falls in love, has Shakespeare, Donne, and Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry (34).

Note that in lovesickness, Woolf refers to the value of literature as reflection, where someone else's words can "speak for" a person, as a surrogate. But with illness, the patient lacks models or a chance to see oneself. The ill person "is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other...so to crush them together that a brand new word in the end drops out" (34).

Arthur Frank, author of *The Wounded Storyteller* and a medical sociologist who studies narrative structures of illness, would call this the Chaos stage. Frank's Chaos Narrative style mimics a sometimes spastic and awkward spitting out of words that lack beginning, middle, and end. Chaos Narrative represents a critical part of illness storytelling, as its nonlinear style is often necessary for formulating later thoughts. Its wisdom is process, more than product. I wrote in the Chaos style in various essays, journals, and poems from 2015-18. I frequently said I "had no words," or when I did, I made up words that sounded more palatable to me than "cancer," like "unicorns" and "binzernix." I called my cancer "the atrocity," my mastectomy "the separation from myself" and "the ravine." When people would ask how I was feeling, I'd often say, "I don't know."

I suspect one reason for this is that the brain has a map of itself. It knows where the arms and legs are. It gets constant feedback from the body about whether it feels healthy or needs attention. So with an amputation such as mastectomy, the primitive/deep brain still believes it has one or both breasts, but the eyes and the logical brain see otherwise. For me, it creates a significant disconnection, even to the point of "phantom breast syndrome," or the feeling that my severed breast still hangs from my chest. This feeling in particular has no words, and though it happens much less often now, when it does, I cannot communicate what is wrong. The desire to dissociate from the body during these times is immense, but as Woolf reminds us, "All day, all night the body intervenes, blunts or sharpens...The creature within can only gaze through the pane" (32-33).

Fortunately, the "unspeakability" and physical/mental dislocation of cancer and mastectomy is becoming more understood by neurologists and psychologists. If patients or literature cannot always verbalize what is wrong, science often can. Bessel van der Kolk, M.D. explains that when the body or brain suffer trauma, such as a major surgery, car accident, or the gunfire of war, Broca's Area, the part of the brain responsible for speech production, loses energy and agency (*The Body Keeps the Score*). Boyer, author of *The Undying*, says that Susan Sontag, in *Illness as Metaphor*, cannot say "I" and "cancer" in the same sentence, as if Sontag redacted the "I" to deal with her cancer (3). She also suggests that Lorde, who is outspoken about her mastectomy, is rare because she does not redact cancer despite being redacted by it (7). While I do not agree with Boyer that Lorde's cancer entirely redacts her (Lorde does live another 16 years after all and travels the world), it indeed seems that most authors, when they are able to write about their mastectomies and overcome total silence, have difficulty integrating the self with the disease and its treatment. This is true even for Lorde. Soon after her surgery, Lorde is aware of a change in personal cohesion: “I want to write of the pain I am feeling right now, of the lukewarm tears that will not stop coming into my eyes--for what? For my lost breast? For the lost me? And which me was that again anyway?” (23). Speaking to the altered sense of bodily integration, she adds, “How do I live with myself one-breasted? What posture do I take, literally, with my physical self?” (47). I, agreeing with Boyer and resonating with Lorde, have found it difficult to maintain my sense of self; in a 2018 essay for a nonfiction class, I wrote that “we cannot simultaneously wish harm upon our cancer while not wishing harm upon ourselves—unless we disown the parts that have cancer. We cannot own and respect our whole selves—including the parts of us that have cancer—unless we dissociate from our breasts.”

Breast cancer and mastectomy have much crossover with trauma theory, hence why mastectomy can be useful in interdisciplinary studies. Trauma is a recalling and reliving of a primary event, often including the original emotions and bodily sensations (Van der Kolk). As I show later, regarding the role literature plays in medical trauma, narrative is a way to give voice to what was previously unspeakable.

I don’t believe all mastectomized women should immediately proclaim their stories, especially where deep trauma occurs. In fact, I contend that there is value in pre-speech. I say this because numerous times per week, I listen to people try to voice their stories in the therapy office about horrific traumas, only for them to come out with guttural “umphs” and “ers” or tears with clenched fists or wildly-waving arms. When this happens, I say, “You have all the time you need, and you don’t have to speak at all,” because I believe there is harm in trying to get people to verbalize trauma before they are ready. Trauma may be alive and well in the body -- just as cancer and illness are -- but to bring it from the body to the lips or the pen, while it still feels “unspeakable,” serves no purpose other than to give the listener false pride in getting a confession or believing an intervention has happened.

So sometimes mastectomy story is about non-words, or what I term the Pre-Integration Phase of story. In Pre-Integration, words may not be uttered at all. Rather, nonverbal forms of communication are used, or even more subtly, a person may not know yet that there is a story to tell at all.

Nonverbal experiences can have benefits, but there comes a time when most mastectomy patients choose to voice themselves, if only in the doctor’s office. The unspeakability and silence surrounding mastectomy does not always last. Frank’s Chaos Narrative, while not narrative or “story” in the true sense, is not usually just “a lump of pure sound,” unlike what beleaguers Woolf’s speechless patient. An early aspect of healing for those who have had a mastectomy is bringing the unspeakability, shame, and grief to a place of sharing. As Stampfl states, “Of course, the traumatized survivor evoking the unspeakable in fact has begun to Speak” (21). Speech, even nonlinear, awkward, spastic speech, can empower.

Lorde and I both wrote Chaos-type journal entries about the days of our respective mastectomies. Coincidentally, both refer to our significant others, as well as disconnected sensory images remembered just minutes to hours before going under anesthesia:

> Lorde: …Then through the dope of tranquilizers and grass I remember Frances' hand on mine...There is the horror of those flashing lights passing over my face, and the clanging of disemboweled noises that have no context or relationship to me except they assault me. There is the dispatch with which I have ceased becoming a person who is myself and become a thing upon a Guerney cart...I remember screaming and cursing with pain in the recovery room…(a nurse) made me a cup of tea and some fruit juice because I was parched (Lorde, *Cancer Journals* 36).

> Me: snow squalls charge across ashy ice; the cab driver squints and apologizes for the weak heater; my wife Candice wears mittens and I can't interlock my gloved fingers inside hers; the undersides of my needle-prodded breasts, my last day with both of them, collect condensed anxious sweat under a too-large sweatshirt...A couple hours later, I tell an anesthesiologist that I'm pretending I'm at the spa, then my thoughts become no thoughts.

Frank describes Chaos Narrative as a blurting of "and then…and then...and then" (*Wounded Storyteller* 99). Thoughts present as disconnected images. In the above examples, Lorde and I both speak in short, random, sometimes unrelated fragments. It is only sometimes afterward that language can be found. This is one main reason why writing about surgery is valuable. Sometimes the words only come once the writing begins.

I recommend poetry as a vehicle for what Frank calls "Disrupted memory...incoherence in the whole which comprises future, present, and past" (*Wounded Storyteller* 60). Poetry is a remedy to the narrative dilemma depicted by Carr, quoted in Frank's *Wounded Storyteller*, who says there is a "practical problem with narrative" which is that "'the past is still viewed in light of its connection to present and future in an ongoing project.'" I suggest that poetry breaks the temporal while still preserving the sick person's disconnected images and feelings. While Frank admits there are limits to focusing on narrative, especially only three forms of it (76), Frank makes little mention of poetry as a bridge between nonspeaking and temporal stories. However, I maintain that poetry should be mentioned in any discussion about how ill people deal with a disconnected sense of time. The lines and breaks in poems render them excellent communicators of Frank's "and then...and then...and then."

Lorde penned significant amounts of poetry. Several of Lorde's poems after 1978 (the year she was diagnosed with cancer) speak of an encroaching mortality. For instance, in "Solstice," she writes:

My skin is tightening
Soon I shall shed it
Like a monitor lizard
Like remembered comfort
At the new moon's rising
I will eat the last signs of my weakness
Remove the scars of old childhood wars

And dare to enter the forest whistling
Like a snake that has fed the chameleon
For changes
I shall be forever.
(*The Collected Poems of Audre Lorde* 328).

Lorde refers to "changes" that insinuate death or at least a significant transition. In the late 1970s, she writes a lot about leaving behind an old self and taking on a new one. In the 1990s (before her death in 1992), she continued to grapple with the possibility of death, while still undergoing treatment. Despite cancer, she continued traveling around the world while writing about her vulnerability. In "Restoration: A Memorial--9/18/91," she draws a parallel between her life and the aftermath of Hurricane Hugo:

Berlin again   after chemotherapy
I reach behind me once more
For days to come
Sweeping around the edges of authenticity
Two years after Hugo blew one life away
Death like a burnt star
Perched on the rim of my teacup… (456).

The theme of big storms correlating with cancer also shows up in my own poetry. It took two years after mastectomy for me to begin writing about cancer. In 2017, I began a series of poems, "Diathesis," comparing my cancer to a series of tornadoes that ravaged my hometown area when I was 13. In one poem, "Taken," I correlate the way tornadoes cut down houses “on one side” of the street the same way the cancer took one side of my chest:

A thirsty swirling entity
Touches down without permission
And cuts away one side of your street
While leaving the other intact.
Leaving you to wonder if it actually happened,
Like how come the roof is still here
But there's a car in the tree?

For me, poetry paved a healing path toward being able to talk about mastectomy. It was easier for me to compare mastectomy, which felt out of control, to tornadoes, which also felt out of control. Instead of writing actual descriptions, metaphor made the topic more approachable. Frank would refer to Lorde’s and my need to write poems as “postmodern:” He theorizes that “the postmodern experience of illness begins when ill people recognize that more is involved in their experiences than the medical story can tell...Postmodern times are when the capacity for telling one’s own story is reclaimed” (*Wounded Storyteller* 6-7).

Not all writers turn to poetry to voice their individual experiences. Before most women talked at all of mastectomy, Frances “Fanny” Burney did so in letters to her sister Esther, circa 1811-12. In the letters, Burney describes her mastectomy, performed without anesthesia. The letters not only showcase various levels of psychological disintegration and reintegration after having mastectomy surgery; they also act as a historicization of breast cancer treatment in the early 1800s. In terms of Chaos Narrative, Burney sometimes uses her letters to make sense of her experience and piece together what happened. Just after doctors ask her to disrobe, Burney writes to Esther the following: “Ah, then, how did I think of my sisters--not one, at so dreadful an instant, at hand, to protect--adjust--guard me--I regretted that I had refused Mme. de Maisonneuve--Mme Chastel--no one upon whom I could rely--my departed Angel!” (“Breast Cancer in 1811”).

One reason the above passage fits Frank’s Chaos style is because it lacks an arc or a planned beginning and end. As a device, Burney uses many em-dashes to punctuate her haste and fear. She also writes in a hurried cadence. Later, she recounts the surgery itself, portraying the sensations in gory but literary detail. While later letters take place over a specific time frame (documenting the surgery, beginning to end), their style is very “in the moment” and grounded in the body, not looking forward or backward. Therefore, they seem to contain elements of Chaos Narrative. For example, Chaos Narrative drives the form of Burney’s writing when she recounts the actual surgery:

> Yet--when the dreadful steel was plunged into the breast--cutting through veins--arteries--flesh--nerves--I needed no injunctions not to restrain my cries. I began a scream that lasted unintermittingly during the whole time of the incision...When the wound was made, and the instrument was withdrawn, the pain seemed undiminished, for the air that suddenly rushed into those delicate parts felt like a mass of minute but sharp and forked poniards, that were tearing the edges of the wound--but when again I felt the instrument--describing a curve--cutting against the edges of the grain, if I may so say, while the flesh resisted in a manner so forcible as to

> oppose and tire the hand of the operator...Oh Heaven!--I then felt the knife rackling against the breast bone--scraping it!...So indescribably sensitive was the spot--pointed to some further requisition--and again began the scraping! ("Breast Cancer in 1811").

According to Epstein, writing was cathartic for Burney, as well as an excision of both physical and mental pain. Epstein hypothesizes, "Because [Burney] is the writer she is also the surgeon. 'Speechless agony' finds words…" (148). Words can be a way to have control over a painful event such as a surgery; Epstein references Montaigne, who journals, "For lack of a natural memory I make one of paper, and as some new symptom occurs in my disease, I write it down" (149). Ultimately, finding language after illness can be "logotherapy," or finding the healing power of writing (150). Burney finds healing in her writing when she "organizes and recasts her experience by transforming it into a historical text; she reopens, relives, and recloses her wound by representing it in writing" (150).

A whole century and a half before Lorde, what Burney reveals about her breast cancer also reveals insight into changes in medicine. The shift from doctors mostly just talking to their patients, to testing, operating on them, and hands-on examining them, was happening at the same time, in a way that reflected increased patriarchal control of medical processes and a movement toward a more objectified way of understanding the human body. One work that highlights the important epistemological transformations occurring in the 1700-1800s is *The Birth of the Clinic* by Michel Foucault. Foucault says, "Modern medicine has fixed its own date of birth as being in the last years of the eighteenth century" (xii). To Foucault, this time period represented a change in focus, called “the gaze,” arising from the anatomo-clinical method, which localized disease pathology and required doctors to do more observation and invasive testing. Heidi Kaye notes that prior to Burney’s time, doctors often relied much on patients’ narratives, rather than putting hands on the patient or diagnosing using instruments like stethoscopes (45). Foucault asserts that the change is not just “the mere surface of contact between the knowing subject and the known object; it is the more general arrangement of knowledge that determines the reciprocal positions and the connexion between the one who must know and that which is to be known” (137). Indeed, as Burney allowed herself to be examined, she was placing herself in a vulnerable position, one where she was not just seeing the doctor, but the doctor was seeing her (Kaye 45).

Such visibility, as well as the intrusiveness of medical procedures themselves, creates a need for separation, space, and control. Even though women usually willingly subject themselves to mastectomy, there is a feeling of having one’s boundaries crossed against one’s will, either by the invasiveness of the malignant tumor itself or by the knife. For me, the operation felt like a deep assault and castration, a loss of personal power at the hands of a powerful male doctor who simultaneously saved me and sliced me. The conflict of being accepting yet resistant, of being free of cancer yet subject to violence, makes mastectomy a very confusing ordeal. The mental schism that occurs, as well as the feeling of being violated and assaulted, are the invisible wounds of mastectomy. However, to write about them is to begin exerting some control over the vulnerability. The gaze of Burney’s doctors, as well as their procedure, “underline her powerlessness, her acquiescence, and the role her body has taken of an objectified entity over which she has lost control, or, rather, that she can only control by narrating (her) history” (Epstein

146). Burney retells her story to "take charge, to survive the ordeal without humiliation" (146).

There comes a time when many patients journey beyond the initial shock of mastectomy and move from Chaos Narrative into visualizing hope and wellness. For this stage, Frank offers two additional narrative forms, the Restitution Narrative and the Quest Narrative. Restitution Narrative carries the message "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (*Wounded Storyteller* 77). Quest Narrative follows a journey, structurally similar to hero tropes, where the patient is on a personal mission to come through sickness as a different person. Quest Narratives consist of three parts: The Departure (the "call"), the Initiation, and the Return (coming through illness changed somehow) (117). Quests have medical events as rites of passage.

Both Restitution and Quest narratives represent moving beyond speaking to make sense of illness into envisioning a larger goal. Lorde's essay "Burst of Light" sometimes exemplifies both narratives. Lorde writes "Burst of Light" after she finds out her breast cancer metastasizes to her liver. After some homeopathic treatment in Switzerland and Germany, she finds that her tumors slightly diminish. As an example of Restitution Narrative, she says, "It feels good to be getting on with my life...a good autumn coming, if I remember to take it easily...I'll be doing another benefit for the Kitchen Table in Boston" (106-107). She looks forward, instead of being caught up in the fear of the now or the pain of the past. Regarding Quest Narrative, "Burst of Light" shows this in passages such as "Personal salvation of any kind is never just personal" (98) and "Battling racism and battling heterosexism and battling apartheid share the same urgency as battling cancer. None of these struggles are ever easy, and even the smallest victory is never to be taken for granted. Each victory must be applauded, because it is so easy not to battle at all" (116-117).

However, I posit that many of Lorde's cancer writings move beyond the Restitution and Quest narratives that Frank promotes. This is because much of *Cancer Journals* and "Burst of Light" utilize a non- individualistic, non- goal-centered approach to dealing with cancer. Apart from Chaos Narrative, which is nonlinear because the patient is just trying to find words for the illness, I propose another narrative form, the Integration Narrative. Integration Narratives depart from Frank's Restitution and Quest narratives in that they focus on pulling together different pieces of the cancer experience into a more "here and now," process versus outcome, type of narrative. Unlike Restitution Narrative, which focuses on the outcome of health, and Quest Narrative, which also implies that the patient is different in the end compared to the beginning, Integration makes room for non-patriarchal, non-goal-centered, and non-"winning versus losing" aspects of living with cancer. Integration is about going inward and deciding what cancer means to us. It is also about connecting various pieces of the experience into a form of acceptance. Acceptance is not acquiescence, it is not admitting defeat, yet it is also not always aspiring, conquering, or moving away from. Integration is not "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" but rather "Yesterday I may have been healthy, tomorrow I may be healthy or I may be sick, but today I am where I am."

Integration Narrative nods toward the more feminine and Black notions of respecting current experience as a teacher. Lorde's *Cancer Journals* and "Burst of Light" exemplify Integration Narrative more often than Restitution or Quest. When Lorde discovers she has liver cancer, she begins to integrate it into her current being rather than disowning it. She muses, “I thought of the African way of perceiving life, as experience to be lived rather than as a problem to be solved” (116). Though she sometimes feels defeated, she tries to live alongside her diagnosis, celebrating the connection of women in her life, continuing to speak, travel, and write.

Lorde speaks a lot about surviving just for today and at times is able to integrate the possibility of impending death. In the following profound “Burst of Light” passage, she neither concedes to death nor shrinks from it: “I am part of two kinds of forces--growth and decay, sprouting and withering, living and dying, and at any given moment of our lives, each one of us is actively located somewhere along a continuum between these two forces” (79). Here, Lorde has accepted the reality of her illness without dissociating from it, as is what happens in Chaos Narrative; she does not hold onto a day of someday being well, as in Restitution Narrative; nor does she vow to transform herself, as in Quest Narrative. She is also long past the Pre-Integration/nonverbal stage I proposed earlier. Instead, she seems to sit alongside her illness and validate it but neither shrinks away nor tries to transform it.

However, as Frank acknowledges, people can cycle back through various stages of understanding illness. As he eloquently observes, “...Narratives are like patterns in a kaleidoscope: for a moment the different colors are given one specific form, then the tube shifts and another form emerges” (*Wounded Storyteller* 76). In a cyclical manner, there may be a need for more than one phase of integration. Integration Narrative can recur when a new illness appears before another resolves, or major life events take place when the original illness has not abated. The need to integrate multiple life challenges happens continually, illness or not. Lorde, for instance, dealt with repeated bouts of cancer. She partly recovered from breast cancer then learned she “had liver cancer, metastasized from the breast cancer” she acquired six years prior (“Burst of Light” 49).

While concurring with Frank about the shapeshifting nature of narrative forms, I suggest additional narrative types that serve purposes other than the ones already described by Frank and myself. I’ve perceived two additional narrative formats. These I term Maintenance Narrative and Reformation Narrative. I find them necessary because illness has blurred edges around it. Sometimes we are more well than sick. All the time, the world interacts with sick bodies, and bodies interact with it.

Maintenance and Reformation Narratives also conform to Frank’s idea of stories changing in “kaleidoscopic” fashion. However, Maintenance and Reformation tend to show up further down the road of one’s illness journey. While Pre-Integration, Chaos, Restitution, Quest, and Integration Narratives all represent some form of movement from unspeakability into verbalization, the Maintenance and Reformation Narratives answer questions about how to live life once the initial illness remits enough to think beyond it, toward either maintaining a “new normal” or creating a better world. I would add that not everyone reaches these last two stages of narrative form. But for those who do, I put them forth in order to extend Frank’s work, so that additional experiences of illness can be recognized. The next section investigates the importance of Maintenance and Reformation Narratives, specifically again through the lens of mastectomy stories.

CHAPTER V

FROM SPEAKING TO LIVING

"Once you've lived, there's also 'how are you going to live? And who do you really want to be when you're not defined by cancer and treatments and follow ups and care?"
(Excerpt from *Cancer Journals Revisited*, a film by Lana Lin)

One of my contributions to the illness narrative dialogue, Maintenance Narrative, happens once a person has integrated illness into life and moves on. The ill person does not forget about illness, but during the Maintenance phase, the person mainly focuses on other aspects of life: Working, traveling, buying groceries, exercising, raising children, and so on. Lorde teaches that everyday activities hold a place of value in dealing with cancer. She says that we have no power over some aspects of our cancer, such as "the air we breathe and the water we must drink" ("Burst of Light" 120), but that we have power where we stand, whether that is "a doctor's office or the telephone company, the streets, the welfare department, or the classroom" (120).

In his Afterword, Frank mentions what he calls the "life-as-normal" narrative (*Wounded Storyteller* 194), but this is not the same as Maintenance Narrative. The main difference is that Frank's term for "life-as-normal" describes patients who mainly deny or want to hide the gravity of illness. They say it has not changed them and that there is no use dwelling on it (195). Life-as-normal differs from Frank’s Restitution Narrative and my Maintenance Narrative in that with Restitution, the person hopes to be well again but does not deny the body’s current state of disruption. It still allows for what Frank says is the need for “witnessing,” or sharing (195). Contrarily, Frank cautions that life-as-normal narrative “risks perpetuating the silences that Audre Lorde spoke against” (195).

With Maintenance Narrative, the person acknowledges having been ill but has worked through integrating and accepting it. The person may still have tests and follow-up care but has mostly moved through illness into the space after it. Maintenance is more a developmental phase after illness than a purposeful negation that illness has occurred.

One reason for Frank’s and my different conceptualizations of “life as normal” may be our professional backgrounds. Though Frank and I have some similarities, a main difference is that Frank is a medical sociologist, while I come to literature studies as a Licensed Professional Clinical Counselor. Frank helps doctors learn Narrative Medicine techniques, teaching physicians to humanize patients; I spend most of my work life helping emotionally-distraught people recreate meaning out of trauma. I borrow the word “maintenance” from James Prochaska’s Stages of Change. Though Prochaska means “maintenance” in terms of people with addictions maintaining sobriety, both I and Prochaska mean “maintenance” in the sense that disruption has already happened and now the person lives a new status quo (University of Rhode Island.edu/“Stages of Change”). Incidentally, Prochaska works at the University of Rhode Island’s Cancer Prevention Research Center.

People tell Maintenance Narratives because their headspace is less taken up with illness than it used to be. They may focus on topics other than sickness, even when the person may still be sick. An example is when Lorde, still amidst treatment for her liver cancer, tells about the office she sets up, “a tiny alcove with an air mattress half-covered with bright pillows, and a low narrow table with a Nigerian tie-dye throw” (122). She meets a woman and talks with her “about the role of art and spirituality in Black women’s lives” (122). Between each bout with cancer, she creates copious amounts of writing not focused on cancer. For instance, *Encyclopedia Britannica*’s biography of Lorde shows that between her mastectomy in September 1978 and “Burst of Light” in 1986, she started a new publishing house, Kitchen Table: Women of Color Press (“Audre Lorde”). She published *Zami: A New Spelling of My Name* in 1982. She produced the essay “Apartheid USA,” where she parallels South Africa with the United States, in 1985. These are just a few examples of the non- cancer-related works Lorde proliferated.

I too entered a maintenance stage. I wrote poems about love, scarecrows, Italy, gun violence, and the upstairs neighbor I had when I was four. I could tell by my journals that I was living life more “as usual” when my entries became fewer, indicating I spent less time privately writing about cancer and more time telling stories out in the world. I dove into improvisational theatre and spouted monologues about beauty spas, the 80s band Journey, and the time my car broke down in a sand dune. However, I still sometimes thought about cancer, especially when I had two suspected recurrences, throwing me back into Chaos Narratives at times.

Now though, six years out from mastectomy, I vacillate between some Quest projects (of which this thesis has elements); times of Maintenance (when I will talk about work, my dog, or the latest plumbing company I’ve hired); and also Reformation Narrative (again, what this thesis often represents). What makes this a partial Quest

Narrative is that I promised myself, after my mastectomy, that I would finally get the master's in English I started in my 20s but never finished. What makes this also a Reformation Narrative is my desire to use my work as a form of education and advocacy.

Reformation Narrative joins the personal and political. It stretches outward into society and mixes individual illness experiences with interpersonal or societal concerns. It interfaces the body with a body politic that may have "othered," shamed, oppressed, or not served the patient's best interests. Reformation is not just accepting one's circumstances or finding peace with them, such with Integration Narrative. Rather, Reformation Narrative is, as its name suggests, about using the cancer experience to heal some part of society, which in turn heals the patient. It redefines one's identity after the person thought it had already been found. Reformation storytellers learn new lessons after thinking they've already learned them all. They acknowledge the interconnection of all beings but also respect their own needs and don't subvert them.

Frank specifies that some sick bodies are "dyadic" bodies (*Wounded Storyteller* 35). He defines dyadic bodies as understanding that "this other has to do with me, and I with it" (35). Dyadic bodies exist for relationships, because suffering sickness alone, without reciprocal understanding, intensifies pain and loneliness. Not all dyadic bodies talk about Reformation, though some certainly do. While I agree that a dyadic body mindset is a healthy way to navigate illness, I go beyond by saying that there is a specific type of narrative that goes beyond relationship with others to that of the community, society, nation, or the world. Frank owns his omission of more politically-motivated types of narrative plots. He acknowledges his three narrative frameworks may not be enough, that he uses three because three is a reasonable number to comprehend, but that "other types of narratives can and should be proposed" (76).

Lorde generates much Reformation Narrative. Most of her cancer writings typify a Reformation language by interweaving her cancer with what she describes as "cancers" of society ("Burst of Light" 116). Lorde compares cancer to various injustices. As an example of Reformation Narrative, she emphasizes,

> I spend every day meditating upon my physical self in battle, visualizing the actual war going on inside my body. As I move through the other parts of each day, that battle often merges with particular external campaigns. The devastations of apartheid in South Africa and racial murder in Howard Beach feel as critical to me as cancer (125).

To Audre Lorde, cancer represents more than a disease that takes her right breast, invades her liver, and eventually ends her life. To me, cancer stands for more than the stealthy plague that killed my grandmother before I was born, stole my aunt at 42, and took my own right breast. Yes, cancer causes grief and fear of death. But cancer also represents an opportunity for revelation and revolution. It is a call for systemic thinking, not just about illness but about the fine line between personal and community/national/world dis-ease.

Various oppressions are illnesses of society, just as cancer is an illness of the body. If we think of embodiment as not just in the individual but also in groups of people, then Reformation stories are ways to simultaneously understand micro- and macro- level diseases. In *Cancer Journals,* Lorde draws the important comparison between silence and sickness. Just as cancer cells intricately weave through the fabric of other tissue, attach to blood and organs, and often make themselves difficult to cut apart from the body ("What Is Cancer?"), so too, according to Lorde and to me, silence and its concomitant fear of difference is a cancer not easily extracted from societal institutions, customs, families, and hierarchies.

One metaphor about cancer that recurs again and again in Lorde's work is about how silence can poison. She implies a direct relationship between silence and disease-proliferation and, simultaneously, between speaking one's truth and unburdening from illness. In an address to the Modern Language Association in 1977, shortly after Lorde's first breast biopsy, which was benign but caused a reckoning with mortality and a reassessment of priorities, Lorde asks, "What are the words you do not yet have? What do you need to say? What are the tyrannies you swallow day by day and attempt to make your own, until you sicken and die of them, still in silence?" (Lorde, *Cancer Journals* 19).

Similarly, she calls not just for better food, reduced pollution, and improved access to medical care, which could reduce cancer rates and mortality (75); she also declares that cancer rates will not improve where and while violence and inequality exist. Referencing the commonly-heard recommendation that cancer patients look for the positives in life and just be thankful to be alive, Lorde says:

> In this disastrous time, when little girls are still being stitched shut between their legs...when 12 year old black boys are shot down in the street at random by uniformed men who are cleared of any wrong-doing, when ancient and honorable citizens scavenge for food in garbage pails...then it is not a wonder that we are not all dying of a malignant

> society. The happiest person in the country cannot help breathing in smokers' cigarette fumes, auto exhaust, and airborne chemical dust (77).

Comparing cancer to apartheid, and publishing journals about the similarities, are other examples of how Lorde uses her disease beyond herself. Her work inextricably weaves into her cancer treatment. Following are some other examples of Lorde's Reformation orientation. They illustrate Lorde's notions of a "malignant society" even further (*Cancer Journals* 77).

Regarding the "cancer" of a society that hides and blames people who are sick instead of allowing them to be open about their maladies: Lorde advises, "I think of how important it is for us to share with each other the powers buried within the breaking of silence about our bodies and our health, even though we have been schooled to be secret and stoical about pain and disease" (*Burst of Light* 118-119).

On the topic of environmental degradation: "For me, my scars are an honorable reminder that I may be a casualty in a cosmic war against radiation, animal fat, air pollution, McDonald's hamburgers and Red Dye No. 2" (*Cancer Journals* 61).

Equating doctors' urgency to have women cover their missing breasts with either reconstruction or prosthesis, with subverting women's status in society: "Attitude towards prosthesis after breast cancer is an index of this society's attitudes towards women in general as decoration and as externally defined sex object" (62).

Similarly, speaking out about the need for different bodies to be accepted as legitimate: "...where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre, a threat to 'morale'" (66).

Finally, and most vociferously, Lorde speaks on behalf of People of Color: “What Woman of Color in america over the age of 15 does not live with the knowledge that our daily lives are stitched with violence...We are equally destroyed by false happiness and false breasts” (78).

Though Lorde appears to also be on a quest toward reforming and revolutionizing various systems, I recognize a distinction between Reformation and Quest Narratives. Yes, those who engage in language around reforming societal institutions may hear what Frank dubs a “call.” They initiate a “road of trials,” and sometimes “return” to a newer, better self as part of a journey (*Wounded Storyteller* 117-119). However, not all Reformation plots promise these three elements. Reformation does indeed often start with a passionate “call” to improve society, but it refuses the difference between personal illness and collective need. Its “road” does not detach itself from societal journeys toward health. Finally, it also does not guarantee a “return” to a better state of health. Instead, Reformation Narrative is less of a journey and more of a mindset or code. It asks for commitment to outer struggles, while not all Quest Narratives do so.

To be sure, Frank understands the link between personal and societal diseases. For example, he believes medical diagnosis obfuscates broader illness. He elaborates, “Society prefers medical diagnoses that admit treatment, not social diagnoses that require massive change in the premises of what that social body includes as parts of itself” (113). Yet his Quest Narrative does not mandate commitment to social causes, while Reformation Narrative, as part of its definition, does. Lorde exemplifies Reformation Narrative when she says, “The struggle with cancer now informs all my days, but it is only another face of that continuing battle for self-determination and survival that Black women fight daily, often in triumph" ("Burst of Light" 49). Tellers of both Quest and Reformation narratives usually talk or write as part of their healing, but patients who espouse Reformation Narratives may or may not expect healing of their insides until the outside world heals as well. Along these lines, a cancerous tumor may be removed, but the sick person, even if "cured," will not feel completely healed while systemic illness still proliferates.

Many ill people do not see wellness as a possible outcome of their stories. Frank says this stands true for people whose illnesses are terminal, who know they may die soon, or for other reasons, such as depression, negative beliefs about the quality of treatment regimens, or secondary gain from a sick role (31). Another possible outcome of illness is that it remits but never resolves. Frank points to the "remission society," or the group of people who are "effectively well but could never be considered cured. These people are all around, though often invisible" (8). Invisibility of mastectomy patients to each other is a large impetus for Lorde's Reformation Narrative; she adamantly asserts that if mastectomized women hide from each other, behind prosthetic breasts or reconstructed ones, they will never find each other. Lorde proclaims, "If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness" (*Cancer Journals* 62).

While Lorde vocally discourages readers from using prostheses or getting reconstructive surgery, very few women, including myself, follow her advice. In my case, though I wish I was as bold as Lorde, I don't want to invite slurs, stares, or commentary about my body. So I insert a silicone prosthetic breast into the pocket of a “mastectomy bra,” sold at a store that specializes in breast cancer items. (A whole industry devotes itself to prostheses, apparel, wigs, and other wares that disguise cancer patients). Still, I agree with Lorde that those of us with mastectomies should find each other and not be “invisible.” How to “come out,” then, about one’s mastectomy remains a need.

I urge those of us with mastectomies to find each other with our voices, opting to talk or write about our bodies. We should do so for ourselves and others. However, various barriers and facilitators to communication exist. In the next section, I investigate a symbol that plays both roles. That symbol is the pink ribbon.

CHAPTER VI

BLACK-AND-BLUE AND PINK

“Live Pink.” (Susan G. Komen Foundation 2021 slogan for its merchandise)

“More Than Pink” (Susan G. Komen 2021 slogan for its fundraiser walks)

(Source: Info-Komen.Org)

Previously, I spoke about what it’s like to not have words for the mastectomy experience. I’d now like to shift toward another angle of unspeakability: The pink ribbon symbol. To be sure, the ribbons do not overtly silence people. Instead, their ubiquitousness and ties to mass corporate marketing campaigns make them a convenient stand-in for narratives that otherwise might be told.

The “Think Pink” slogan first hit the breast cancer fundraising scene in 1996 (“How Did Think Pink Begin?”). Lorde died in 1992 (*Encyclopedia Brittanica*). While impossible to conjecture what Lorde would say about the trend of pink ribbons and products since her death, Lorde does speak loudly against the American Cancer Society and other organizations that use women for organizational gain (*Cancer Journals* 73). Pink ribbons have come to mean “breast cancer awareness.” The awareness of it is everywhere, but awareness is not the same as sharing experiences, the fear of death, the bodily dysmorphia, the burns from radiation, the lymphedema from loss of lymph nodes, and the infertility from chemotherapy. Do pink ribbons create a space for stories or silence them? In my experience, both hold true.

Unlike Fanny Burney's time (late 1700s/early 1800s), or even Lorde's time (1934-1992), the words "breast cancer" are currently more acceptable. For example: "My aunt has breast cancer." "I'm running a charity race for breast cancer." This is in part due to the mass distribution of the pink ribbon symbol on products all across America. Pink ribbons appear on apparel (such as t-shirts, shoes, hats, and scarves); food packaging (KFC buckets of chicken, Tic-Tac mints, Yoplait Yogurt, Hamburger Helper); and countless other products (Quilted Northern Bath Tissue, Avon cosmetics) and places (such as being paired with the NFL logo and painted onto the 50-yard line at professional football games). There are websites devoted strictly to the sale of pink ribbon products (like choosehope.com). There are even pink ribbons with pink ribbons (such as the "breast cancer awareness print grosgrain ribbon for hair bow/hair clip accessories" sold by the Midi Ribbon Company on Amazon.com). Beyond pink ribbons, the color pink itself is now synonymous with breast cancer. For instance, companies such as Hershey's make pink foil Kisses (without the ribbon emblem); the 150-feet high spray of water in the fountain at Point Park in Pittsburgh, PA is dyed pink during the whole month of October; car dealerships make special pink cars; there are pink shoes worn by sports stars, even pink drill bits used by the fracking/oil company Baker Hughes. Boyer sees so much pink around her that she says,

> At least in the age of “awareness,” that lucrative, pink-ribbon-wrapped alternative to “cure,” what we are told must be given up for the common good is not so much one’s life as one’s life story. The silence around breast cancer that Lorde once wrote into is now the din of breast cancer’s extraordinary production of language. In our time, the challenge is not to speak into the silence, but to learn to form a resistance to the often obliterating noise (8)

Boyer’s claim that “one’s life story” must be given up resonates much with my own questions about whether the “pinking” of breast cancer helps or hinders storytelling. However, I stray from Boyer by suggesting that the “silence” and the “noise” are actually the same. Yes, so much “awareness” occurs at the universal level that individual, micro-level experiences get drowned out and silenced in a paradoxical fashion. Yet sometimes the “noise” creates a comfort barrier between patients and their illnesses when they are either not ready or do not yet know how to speak. I agree with Stampfl when he suggests, “I seemed to discover in the unspeak- able a kind of magic carpet, an instrument for passing smoothly and convincingly from the universal to the specific” (19). The very universality of pink ribbons simultaneously promotes a feeling of camaraderie about breast cancer while opening doors for isolated people to recognize each other. I conclude that pink ribbons play very different, not necessarily compatible roles: Perhaps they make some people feel less alone. They may also do the opposite, making patients feel like a number, an invisible body, or a corporate pawn. Journalist Barbara Ehrenreich, who also suffered mastectomy, laments, “Now breast cancer has blossomed from wallflower to the most popular girl at the corporate charity prom” (“Welcome to Cancerland”).

While the pros and cons of corporate opportunism and cause marketing is not the subject of this paper, it should be noted that the result of so much marketing is that it may become old hat, over-recognized, and therefore the ribbons then become invisible. Additionally, the ribbons are such a widespread signifier that Jacques Derrida’s theories of “decentering” come to mind. Derrida, when he refers to the “structurality of structure” (517), reports that structure is important for limiting the amount of “freeplay” or possible tangents, but that ultimately what seems like the center of a structure is outside the structure itself. In the case of breast cancer, this could mean a.) that breast cancer was the original “center” but has been replaced by the ribbons or b.) that pink ribbons have become such a center that they have been replaced with other meanings, such as the “corporatized opportunism” I mentioned earlier. Frank talks about the rise of pink ribbon discourse in “From Sick Role to Narrative Subject.” He says his paper is an example of shifting meanings of pink ribbons because he adds them to a new area he’s studying. The new area is the three-way intersection of pinkness with the respective discourses of illness experience and institutional medicine (17). He therefore adds to ribbons’ potential utility while also decentering them away from breast cancer product labels and patients themselves. Likewise, my own thesis may shift the centralization of pink ribbons by placing them alongside discourse about storytelling and silence.

Again returning to the topic of mastectomy, note a pink ribbon in Figure 1, then note the scarred chests of the women in Figure 2. Both are images; both can be signifiers; but which image stands best for what? How may each image silence or create dialogue?

Figure 1 Pink ribbon

Figure 2 Four women with double mastectomies

Visual images simultaneously say nothing yet “say” more than words can. The different images, both representing breast cancer, can bring about new dialogues, especially when placed in conjunction with each other. They can also stand in when no words are possible. Pink ribbons, while representing breast cancer and not mastectomy in particular, can signify multiple words, both with positive and negative connotations. While I dislike ribbons’ use by corporate advertising campaigns, their nature as images rather than words can speak into silence for people who may otherwise not know how to talk about their disease. Regarding the image of women with chest scars, it too can both silence and generate conversation. It shows a more actual view of mastectomy, literally depicting it in its true form, not “pinkwashing” its reality. However, the image’s realism may also have the effect of being too shocking, honest, or taboo, therefore dissuading people from using it to spark dialogue. Additionally, its broad signification may reduce the need for words, telling all that patients would say when describing their surgeries. People have asked me “what a mastectomy looks like” or what kind of scar I have; out of gaucheness and modesty, I typically refer them to photographs of mastectomized women rather than describing my own body. I welcome this option not just when I feel uncomfortable telling my story but also when I do not want to sugarcoat what mastectomies look like.

Embarrassed or emboldened, patients in the Pre-Integration stage of mastectomy narrative need this phase of “pre-story” and the right to carve boundaries of no-words around their experiences. Even six years after my own surgery, there are times when I return to Pre-Integration, as the process of talking about one’s mastectomy is not linear. Sometimes silence is needed to catch one’s breath, to accommodate a new memory, or heal from a potential recurrence of disease. However, I sometimes attend the Komen breast cancer walks, to feel solidarity and meet other breast cancer patients, so I can share and listen to many cancer journey stories. I also mindfully wear pink ribbon attire, such as the lapel pin on my jacket or the "Survivor" t-shirts the Komen Foundation gifts patients at walks. I wear these because I want to be found by other patients and have a chance to answer questions asked by non-patients. I also view pink ribbons as "coming out" opportunities that break the ice about my breast cancer history, in much the same way I wear a rainbow pin or shirt to disclose my LGBT status.

Yet breast cancer and mastectomy only share some commonality. Most mastectomy patients have had breast cancer, but only some breast cancer patients have had mastectomy. One reason for mastectomy's uniqueness comes from its paradoxical hiddenness and publicity. Mastectomy is known because breast cancer is widely-publicized, but mastectomy itself generally isn't celebrated with ribbons or touted with awareness campaigns. The social and political experiences of each kind of patient differs.

Nonetheless, if we follow Lorde's lead, it is possible for each woman with breast cancer to advocate alongside others, in her own way. Some women may buy pink products, others may attend environmental rallies, others may raise money for charity, others may write, and others may simply live. Lorde highlights the need to celebrate differences while also challenging traditional ways of disrupting "malignant" systems. Lorde proclaims, "The master's tools will never dismantle the master's house." This means dealing with cancer and its "othering" requires "interdependency." It means, "Those of us who stand outside the circle of society's acceptable women" must learn "how to make common cause with those others identified as outside the structures in order to define and seek a world in which we can all flourish" (*Your Silence Will Not Protect You* 91). This occurs woman by woman, day by day, small action by small action, story by story.

CHAPTER VII

CONCLUSION AND FUTURE IMPLICATIONS

Mastectomy causes a pervasive “othering” not discussed much in other intersectional literature. It creates its own category of difference. Note here that this paper even uses the words “breast loss” and “breasts” -- making two breasts seem like the default correct number, because the pair is deeply-embedded into our language and consciousness.

Talking and writing about mastectomy plays an extremely important role for mastectomy patients. Periods of silence also have their place. After surgery, patients move through various stages of grief and emotion. We seek, among other needs, models, catharsis, connection, and a chance to impact others. We use various narrative structures, depending on our needs, level of illness, and values.

While the structures put forth by Frank and myself cover many mastectomy patient scenarios, we don’t account for all possible types of mastectomy stories. One aspect of this topic that I do not address is the family’s side of the story. Just like patients, family and loved ones also feel isolated, afraid, and impacted by mastectomy and the medical system. Another facet of the subject I omit is educational text, written from a more nonfictional or medical perspective, which tells information such as how to find a doctor, what types of breast cancer exist, how to perform a breast self-examination, and so on. Additionally, other types of narratives not seen here are fictional stories, co-told or co-written narratives, text merged with visuals, and music, screen- and stage plays, and other forms of media.

This thesis discusses how mastectomy overlaps with feminism and gender studies, with some attention to trauma studies as well. Additionally, while I identify with queer people and believe mastectomy is non-normative, a prospect for further study would be to find authors who speak to how breast loss queers the body and changes dynamics of sexual expression. Finally, Reformation Narrative, especially as related to Lorde, implies some intersection with Black studies, but this area deserves further exploration. Mastectomy for BIPOC may be experienced differently and accepted or feared differently, due to BIPOC bodies having different interactions with the medical system that I have not experienced.

One area of study garnering more attention in 2021 is the relationship between mastectomy and colonization of the body. Boyer's work and newer books, such as Elinor Cleghorn's *Unwell Women*, call attention to how Western medicine claims domain over bodies, especially women's bodies. Mastectomy still very much occupies a major component of breast cancer care, and while anesthesia may have improved, women who refuse certain treatments due to pain or side effects are marginalized, compared to women who completely comply with treatment.

Nonetheless, despite the challenges of mastectomy, it sometimes saves lives, and feelings of isolation and bodily estrangement can get better. The stories and examples of others can help us see that. Lorde, whose words I’ve sometimes clung to, said she wrote to remember her story, so that she, “or anyone else in need or desire, can dip into it at will if necessary” (*Cancer Journals* 53). Now I too write to remember, break through silence, and pass on my story to anyone who needs it.

WORKS CITED

“Audre Lorde: American Poet and Author.” Brittanica.com. https://www.britannica.com/biography/Audre-Lorde. Accessed 13 Sept. 2021.

Balaev, Michelle. “Literary Trauma Theory Reconsidered.” *Contemporary Approaches in Literary Trauma Theory*, edited by Michelle Balaev, New York, Palgrave Macmillan, 2014, pp. 1-14.

Benjamin, Walter. *Illuminations*. Kindle edition. Translated by Harry Zohn, Mariner Books, 2019.

Boyer, Anne. *The Undying*. New York, Picador, 2020.

“Breast Cancer in 1811: Fanny Burney’s Account of Her Mastectomy.” *The New Jacksonian Blog*.newjacksonianblog.blogspot.com/2010/12/breast-cancer-in-1811-fanny-burneys. Accessed 7 Nov 2018.

“Breast Cancer Ribbon.” Flyclipart.com. https://flyclipart.com/breast-cancer-ribbon-free-pink-ribbon-clip-art-791640. Accessed 12 Aug 2021.

Butler, Judith. *Bodies That Matter: On the Discursive Limits of ‘Sex.’* New York, Routledge, 1993.

Cancer Journals Revisited. Directed by Lana Lin, performances by Ericka Hart and Elizabeth Lorde-Rollins, Women Make Movies, 2018.

“Cancer Prevention Research Center.” University of Rhode Island. web.uri.edu/cprc. Accessed 12 Sept. 2021.

Cleghorn, Elinor. *Unwell Women: Misdiagnosis and Myth in a Man-Made World*. New York, Dutton, 2021.

Derrida, Jacques. “Structure, Sign, and Play.” https://researchguides.csuohio.edu

/ld.php?er_attachment_id=966143. Accessed 3 May 2021.

DeShazer, Mary K. *Mammographies*. https://muse.jhu.edu/chapter/899467. Accessed 23 July 2021.

Ehrenreich, Barbara. "Welcome to Cancerland." Harpers.org. https://archive.harpers.org/2001/11/pdf/HarpersMagazine-2001-11-0075358.pdf?AWSAccessKeyId=AKIAJUM7PFZHQ4PMJ4LA&Expires=1568333045&Signature=HWjBLPajQSIfCgZFDl1dhshivZc%3D. Accessed 8 Oct. 2021.

Foucault, Michel, 1926-1984. *The Birth of the Clinic : an Archaeology of Medical Perception*. Tavistock, 1973.

Frank, Arthur. "From Sick Role to Analytic Subject: An Analytic Memoir." https://journals-sagepub-com.proxy.ulib.csuohio.edu/doi/pdf/10.1177/1363459315615395. Accessed 22 July 2021.

---. *The Wounded Storyteller*. University of Chicago Press. 2nd ed., 2013.

"How Did Think Pink Begin?" Norcalthinkpink.org. https://www.norcalthinkpink.org/breast-cancer-facts/how-think-pink-began/. Accessed 11 Oct. 2021.

Info-Komen.org. "More Than Pink Walk."https://secure.info-komen.org/site/TR?fr_id=8700&pg=entry. Accessed 11 Oct. 2021.

Jones, David M.D. and Nimbkar, Suniti. "The Wound Which Has Lacerated My Breast Cannot Be Healed." http://www.abigailadamsbirthplace.com/wound-lacerated-bosom-healed-abigail-adams-smith-evolution-treatment-breast-cancer-colonial-america-today/. Accessed 6 Aug 2021.

Lorde, Audre. *Burst of Light*. Fire Brand Books, 1988.

--- "Apartheid U.S.A." In Burst of Light. Fire Brand Books, 1988.

---. "Burst of Light." In *Burst of Light*. Fire Brand Books, 1988.

---.*Cancer Journals: Special Edition*. Aunt Lute Books, 1997.

---. *The Collected Poems of Audre Lorde*. W.W. Norton and Company, 1997.

---. *Your Silence Will Not Protect You*. Silver Press, 2017.

Mathiasen, Helle. "Mastectomy Without Anesthesia: The Cases of Abigail Adams Smith and Fanny Burney." https://www.amjmed.com/article/S0002-9343(11)00096-9/pdf. Accessed 6 Aug 2021.

Mukherjee, Siddhartha. *The Emperor of All Maladies*. London, Fourth Estate, 2011.

Rich, Adrienne. "A Woman Dead in Her Forties." Poeticus.com. https://www.poeticous.com/adrienne-rich/a-woman-dead-in-her-forties. Accessed 3 Aug 2021.

Stampfl, Barry. "Parsing the Unspeakable in the Context of Trauma." *Contemporary Approaches in Literary Trauma Theory*, edited by Michelle Balaev, New York, Palgrave Macmillan, 2014, pp. 15-41.

Van der Kolk, Bessel. *The Body Keeps the Score*. Kindle Edition. Penguin Books, 2015.

Wall, Sarah. "An Autoethnography on Learning About Autoethnography." International Journal of Qualitative Methods (June 2006). https://doaj-org.proxy.ulib.csuohio.edu/article/9b1101150df847d383e4364d28d76539. Accessed 18 Aug 2021.

"The Women Who Showed Their Breast Cancer Scars." https://www.nytimes.com/2016/11/04/insider/the-women-who-showed-their-breast-cancer-scars.html. Accessed 12 Aug 2021.

Woolf, Virginia. “On Being Ill.” Thenewcriterion1926.wordpress.com. https://thenewcriterion1926.files.wordpress.com/2014/12/woolf-on-being-ill.pdf. Accessed 6 Aug 2021.

Yick Flanagan, Alice. “Cancer Screening Among Racial/Ethnic Minority Women.” Netce.com.https://www.netce.com/coursecontent.php?courseid=1929&productid=7274&scrollTo=chap.6. Accessed 10 Aug 2021.