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Student Name: Mennaallah Ibrahim Taher Student AUC email address: menna t@aucegypt.edu Student ID: 900050741

The American University in Cairo School of Humanities and Social Sciences

Beyond the Straightforward Illness Narrative

A Thesis Submitted by

Mennaallah Ibrahim Taher

Submitted to the Department of English and Comparative Literature May 2, 2020

In partial fulfillment of the requirements for The degree of M.A. in English and Comparative Literature

has been approved by

[Name of supervisor] Ferial J. Ghazoul Thesis Supervisor

Affiliation: ECLT, AUC Date: May 20, 2020

[Name of first reader] Balthazar Beckett

Thesis first Reader Affiliation: ECLT, AUC Date: May 20, 2020

[Name of second reader] Megan MacDonald

Thesis Second Reader Affiliation: ECLT, AUC Date: May 20, 2020

Dr. [Name of department chair] Ferial J. Ghazoul

Department Chair Date: May 20, 2020

Dr. [name of Dean] ______
Dean of HUSS Date

Beyond the Straightforward Illness Narrative Menna Taher

Abstract

While the initial premise of Medical Humanities was to encourage more writings about the illness as lived experience, and to include literary works in the curriculum of medical schools, a second more critical wave has emerged that delves deeper into issues of race, class and gender. As the illness memoir has become a genre, the act of writing about illness is not a feat anymore, and illness narratives now demand more complex questions.

Primarily dealing with questions on form and narrative, the thesis tackles major oft-cited works on illness like Tolstoy's *The Death of Ivan Ilyich*, Virginia Woolf's *On Being Ill*, Susan Sontag's *Illness as Metaphor* as well as Audre Lorde's *The Cancer Journals*. However, it also analyzes the recently published book, *The Undying* (2019), by the American poet Anne Boyer. The thesis also briefly taps onto Arabic works like Amal Dunqul's hospital poetry as well as autobiographies of Radwa Ashour and Ni'mat al-Buhairy.

The Death of Ivan Ilyich by Tolstoy and Anne Boyer's The Undying, serve as a representation of first and second waves of the medical humanities, respectively. The comparison between the two works through the concepts of "the universal" and "the specific" guides the thesis. While the universal approach is important, it still has its limitations that are highlighted by a text like Boyer's, which deals with the specific culturally-gendered disease, breast cancer. Audre Lorde's The Cancer Journals, and Anne Boyer's The Undying, which blend hybrid genres, tackle breast cancer in a myriad of ways; through the personal, political, philosophical, and aesthetic. While both powerful works, they are also a part of a woman's life writing tradition, a tradition that now encompasses a numerous works by women writing about their illnesses.

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Introduction

Illness is one of the most universal experiences of human life. The inevitable decay of the body is one of humankind's inescapable tragic truths. It is then no wonder that one of the frequently-quoted statements in writings on illness is Susan Sontag's opening lines of *Illness as Metaphor*: "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (3). Despite the universality of this truth, telling the story of one's illness throughout literary history has never been simple. What does it mean to tell the story of one's illness? how can one best capture it? and how does illness demand a more flexible literary approach? These are some of the questions I intend to explore in my thesis.

One of the first writers to fully probe questions of what it means to write about illness is Virginia Woolf in her 1926 essay *On Being Ill*. Sara Pett considers Woolf's text to be "the first published essay devoted to the representation of illness in English literature," despite noting that some previous attempts have been made (26). Initially titled "Illness: An Unexploited Mine," the essay considers how illness prompts a writer to invent a new language, a language that has not been yet used to describe the experience of illness. Woolf also considers how the ill will turn to poetry and find their taste leaning towards literature that is "sudden, fitful, intense" (20). The essay's popularity lies in the claim that illness has not been among the great themes in literature, a claim that can no longer be true in the contemporary literary world, as the "illness memoir" has become a genre of its own. However, the essay's arguments still cannot be dismissed as outdated. The "how" to write about illness is a much more complex question than just demanding it to be written about as a theme. Even with the proliferation of illness narratives,

Woolf's questions on the language and form of illness writings still endure. To what extent has current literature on illness followed Woolf's footsteps?

In 1978, another important book on the theme of illness and literature emerged, Susan Sontag's *Illness as Metaphor*. As one of the key theoretical works on illness, *Illness as Metaphor* considers the representation of illness and considers how totalizing metaphors mire the reality of illness. Sontag chronicles how tuberculosis (TB) and then cancer were fraught with metaphors that try to compensate for their mysterious nature and causation. While TB was considered the disease of the romantics, who were too pure for this world, cancer patients were depicted as repressed. Sontag also reflects on how these illnesses are used as metaphors. Cancer metaphors, for instance, have been appropriated in military speech on warfare. Sontag reflects on how these metaphors are harmful both on the personal and public sphere. They undermine the patient's experience and allow for the simplification of political rhetoric:

Trying to comprehend "radical" or "absolute" evil, we search for adequate metaphors. But the modern disease metaphors are all cheap shots. The people who have the real disease are also hardly helped by hearing their disease's name constantly being dropped as the epitome of evil. Only in the most limited sense is any historical event or problem like an illness. And the cancer metaphor is particularly crass. It is invariably an encouragement to simplify what is complex and an invitation to self-righteousness, if not to fanaticism. (85)

Despite the apparent difference of their views on illness, Sontag's and Woolf's writings on illness can still be seen as complementary. It is true that Woolf's view on illness can be considered as that same romantic view, which Sontag derides. However, Woolf still captures her

"romanticized" view of illness through embodying a sick person's lived experience, not through evading or denying it. Woolf writes for instance:

In illness this make-believe ceases. Directly the bed is called for, or sunk deep among pillows in one chair, we raise our feet even an inch above the ground on another, we cease to be soldiers in the army of the upright; we become deserters. They march to the battle. We float with the sticks on the stream; helter-skelter with the dead leaves on the lawn, irresponsible and disinterested and able, perhaps for the first time for years, to look round, to look up--to look, for example, at the sky. (12)

In the passage above, military terms are reversed. The sick role is one that defies the norms of warring expansion. Instead of giving the ill a passive role, Woolf depicts the ill as subversive "deserters," who can give us the ability to look at the world differently. She does so by describing illness as a lived experience as opposed to the myriad depictions of illness as metaphor or allegory—depictions that Sontag delved extensively into in her analysis. Relaying illness as lived experience lies at the heart of Medical Humanities, and perhaps both of these theoretical texts include the kernels for the interest in the narratives of patients.

Currently, written accounts of all kinds of illness and disabilities are published annually. After the surge of HIV autobiographies in 1980s and 1990s, illness narratives became a genre of their own in the late twentieth century (Jurecic, *Illness as Narrative* 2). Medical schools have also started including literature about illness and patients' stories in the curriculum to inspire students to become future empathetic doctors or medical practitioners (Jurecic, "Empathy and the Critic" 11). Several theoretical books have emerged that emphasize the importance of telling an illness story including Arthur Frank's *The Wounded Storyteller* (1995), and more recently

Rita Charon's *Narrative Medicine: Honoring the Stories of Illness* (2008). In *The Wounded Storyteller*, Frank considers how an ill body begs for a story to be told. He considers telling a story of illness as an "act of witness," (40) which brings together the community of the ill. Rita Charon, one of the main propagators of narrative medicine, writes about the utilitarian aspect of storytelling and its therapeutic effects. Charon writes from the point of view of a medical doctor, and about the failure of the modern medical field to listen to patients and the importance of doctors to build narrative skills. She explains the term "narrative medicine" as follows: "I use the term *narrative medicine* ¹ to mean medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness" (4).

However, some critics, including Jurecic, have shown dismay at the way that literature is currently taught at medical schools, and emphasized that reading a few sets of stories will not automatically transform doctors into more empathetic medical practitioners. Another issue highlighted in Arnold Weinstein's "The Unruly Text and the Rule of Literature" is the tendency of medical schools to teach realist literary texts and stray from more "experimental, avant-garde, or postmodernist texts" (1). The article is one of many about "unruly texts" in a special issue in *Medicine and Literature* journal (1997), an issue edited by Charon herself. Rebecca Garden questions the idea of empathy itself, as she believes that telling patients' stories does not necessarily eradicate the power dynamics inherent in medical institutions, and the structural inequality of the system.

How does one then deal with the need for such stories to be told, and at the same time with the problems that arise with the ubiquity of such stories without much critical insight? In her book *Illness as Narrative* (2012), Jurecic relays current debates on the importance of illness narratives. On the one hand, medical humanism considers illness stories for their utilitarian

function and fails to tackle them critically, and on the other hand, literary criticism with its hermeneutics of suspicion, dismisses illness memoirs as "victim art" and fails to consider the reasons why such stories matter to people. She writes: "Literary critics' disdain for or disinterest in illness memoirs suggests, above all, that contemporary critics have become alienated from ordinary motives for reading and writing" (3). Jurecic tries to find a common ground between both views and does not dismiss either view entirely.

In *The Undying*, a memoir about her breast cancer experience, published in 2019, Anne Boyer negotiates between these two opposing viewpoints. On the one hand, she writes out of a need to tell her story, and, on the other hand, she questions the importance of writing yet another illness story, and the implications of doing so untruthfully, or worse, in a way that would "propagandize for the world as is" (116). Boyer writes her memoir in a climate saturated with breast cancer stories that follow a preordained narrative usually ending with a note of triumph. *The Undying* could have been easily written like that--especially since Boyer survives at the end. However, even in her survival she relays the multiple deaths she undergoes during the process, making a triumphant end almost impossible in her tale. However, what disrupts the clear-cut narrative is also the form with which it is written. Difficult to define, and encompassing different genres, the book poses questions on illness and form—questions that have been perhaps asked since Woolf's *On Being Ill*.

What one can trace throughout critical works written on illness writing, is the recurrence of the question on form. Ever since Woolf declared that "[i]llness makes us disinclined for the long campaigns that prose exacts" (19), writers still probe on how to actually capture this experience. In the Introduction to Alphonse Daudet's *In the Land of Pain [La Doulou]*—written before Woolf's *On Being Ill*, but published posthumously a few years after in French in 1930—

its translator Julian Barnes agrees that "long prose" is perhaps not the most appropriate form to reflect illness:

La Doulou, though organized, and with a certain inevitable plot-progression, remains a collection of notes; but this isn't necessarily a disadvantage. Notes seem an appropriate form in which to deal with one's dying. They imply the time, and the suffering, which elapses between each being made: here is a decade or so of torment reduced to fifty pages. Notes minimize the danger of Brodkeyism; also the temptation to disguise, to make too much art of it all. (xiv)

There are differences of course in both statements. One believes that illness needs "more intense" literary works to describe its extraordinary state, while the other believes that brevity will bring out the rawness of the experience.

Nowadays most writers choose the form of the memoir to write about their illness. However, the autobiographical essay, which can be partly a memoir, but also a hybrid of several other forms is starting to garner attention in illness scholarship. Ann Jurecic in her article "The Illness Essay," suggests that the essay is a fitting form for illness. She questions why the essay has not taken the same attention that other literary forms have. Through presenting the ideas of John D'Agata on the essay--on the malleability and the experimentality of the form that generally revolves around questions posed rather than a clear narrative--Jurecic finds the essay a fertile ground for exploring the theme of illness. She writes: "If uncertainty and the unknown are the foundation of the essay as a genre, then illness is a fitting subject. The disruptions of illness inspire the practices that D'Agata identifies as foundational to the essay, among them questioning, contemplation, deliberation, and, of course, writing" (17). The essay cannot be easily categorized and can fall under varied genres; in a book of essays one could find lyrical

prose followed by facts, followed by some stream-of-consciousness thought patterns. Its hybrid nature allows for the complexities and multi-layered nature of illness—the deeply personal, the universal as well as the cultural, political and social--to be fully explored.

Perhaps what the above suggests is not that there is a perfectly fitting form for writing on illness, but that instead, illness demands questions to be posed on form. Yet before writing about how form informs narrative, perhaps it is important to also dissect the large term "illness." As stated at the beginning, illness is one the most universal aspects of human life, but does that mean that all illnesses are alike? To term something as universal because it inflicts damage to most people, does not mean that it is unvarying. Not only does every single illness have its own specificity, but such specificity changes depending on the historical era when it occurs. Yet even that is not enough of a categorization, because the triad of race, sex, and class affects the illness experience as it does with most of human interactions. In the introduction of the *Edinburgh Companion to the Critical Medical Humanities* (2016), Anne Whitehead and Angela Woods offer a comparison between the initial premise of Medical Humanities and its more critical evolvement:

Investigations of this scene [the clinical encounter between doctor and patient], whether empirical, philosophical, literary or historical, have placed a humanist emphasis on individual protagonists and the role of narrative, metaphor and gaps in communication within the dynamics of the clinical interaction. A focus on the lived body of the cancer patient qua patient has tended to divert attention away from dimensions of gender, class, race, sexuality and debility within this scene; the specific health policies and practices that shape it in time and place; and its material and economic underpinnings. (2)

Tolstoy's *The Death of Ivan Ilyich*, a work in the "so-called canon of literature and medicine" (Charon and Taylor vii) that deals with "the clinical encounter between doctor and patient," is then a good starting point to reflect upon the two waves of Medical Humanities. While developing the second more critical wave in the analysis of works chosen in the thesis, I will also address what is important about the initial premise of Medical Humanities.

In introducing my theme, I will compare Tolstoy's The Death of Ivan Ilyich (1886) to Anne Boyer's *The Undying*, two works that represent the two waves of the Medical Humanities. However, the comparison is not an attempt to consider one work superior to the other, rather it highlights the limitations of a powerful narrative like Tolstoy's. Boyer's book, because it was initially intended as a book on the politics of care, can be used to emphasize Tolstoy's blind spot. Boyer also situates herself in contemporary America, showing how her own experience of illness cannot be removed from these particularities. In the following chapters, I will delve more into the culturally gendered disease of breast cancer through a classic of illness literature, Audre Lorde's *The Cancer Journals* (1980), and Anne Boyer's *The Undying*, a book recently published, to reflect on the changes of breast cancer culture. While there are many similarities between both works, each is written in a completely different climate with a different intention. Lorde writes in the 1980s when there weren't many autobiographical accounts written about breast cancer. She also writes from the first-person viewpoint of a lesbian black woman, who was systematically silenced throughout history. Boyer, on the other hand, writes in a climate saturated with illness stories, and where breast cancer culture enforces a standard optimistic type of narrative, which Barbara Ehrenreich as well as other critics have admonished. In the third and final chapter I will explore how illness writings by women intersect with feminism, and how Lorde's and Boyer's autobiographies are part of a larger women's tradition of life writing, and more specifically,

illness writing. I will return to Woolf's views on illness and language to consider linkages between Woolf, and Lorde and Boyer, and how they—as Woolf imagined—create a language and form for illness, but also how they go beyond her initial premise to tackle pressing political issues.

Chapter 1

The Illness Story:

Between the Universal and the Specific

Pain — has an Element of Blank — It cannot recollect
When it begun — or if there were
A time when it was not —

It has no Future — but itself — Its Infinite realms contain Its Past — enlightened to perceive New Periods — of Pain.

--Emily Dickinson

Dickinson and Daudet: Two Approaches of Writing about Pain

Emily Dickinson's poem (1890) cited above refers to pain abstractly. The power of this poem lies in its ability to write about pain in its totality and not about a specific type of pain. The poem can apply to a mother grieving a child, as much as to a person undergoing chemotherapy, because it captures the essence of what it is to be in pain—its vastness and on-goingness, and its ability to carve for itself a different temporal dimension. While Dickinson has masterfully encapsulated the grand concept, one still cannot deny the stark difference between emotional pain and physical pain. While emotional pain lies at the heart of all literature, detailing the overpowering feeling of bodily pain has eluded writers and philosophers, alike.

One of the most important works written on the topic is Elaine Scarry's *The Body in Pain* (1985). Scarry writes about the political implications of bodily pain, and torture more specifically. However, in her introduction Scarry writes about bodily pain in general. She begins

10

her book with a striking analogy about another person's pain being "as distant as the interstellar events referred to by scientists" (3). She writes about the impossibility of sharing the pain one feels with others, and how there is doubt or an inability to grasp it when it comes to another person's pain. In the medical context, she has also written about how doctors rely more on data like x-rays and blood samples than a patient's account of pain, which they consider unreliable. This can result in inadequate care for a patient (6-7). However, there have been attempts noted by Scarry to surpass the inexpressibility of pain. The "McGill Pain Questionnaire," for instance, has aided patients in describing pain not only in its intensity, but enabled patients to specify its sensation. The questionnaire includes various adjectives along the spectrum of "temporal," "thermal," and "constrictive" types of pain such as: flickering, scalding, or gnawing, respectively (7-8). Yet despite the difficulty of expressing physical pain, artists have still made attempts to convey it. When language fails, sometimes other means can be more expressive. One interesting example relayed by Scarry is Ingmar Bergman's use of background color in his 1972 film *Cries and Whispers*. Scarry writes:

Bergman's *Cries and Whispers* opens with a woman's diary entry, "It is Monday morning and I am in pain," and becomes throughout its duration (a duration that required that its cinematographer photograph two hundred different background shades of red) a sustained attempt to life the interior facts of bodily sentience out of the inarticulate pre-language of "cries and whispers" in to the realm of shared objectification. (10-11)

Despite Scarry's acute observation, the film still cannot be reduced to an expression of a cry of pain. The film revolves around the relationship between three sisters, as one of them, Agnes, is dying of cancer. While physical pain can sometimes override all else, especially in its acute

moments, when all a patient wants is for it to cease, an experience of illness is much more than a patient having to carry the burden of pain. In order not to fall in the trap of Cartesian dualism, and make a clear distinction between psychological and bodily pain, perhaps it is also important to mention the film's memorable closing scene. The scene depicts yet another diary entry of the sister who had by then passed away. It renders a tranquil moment, in between the long duration of suffering, when everything seems to be perfect. The sister's aches and pains are momentarily subdued that she could even manage to sit outdoors for a while. Agnes describes this moment, of closeness to her two sisters and proximity to nature, as the epitome of happiness. This scene brings out the varied shades of an illness experience, and how the physical and psychological are inextricably intertwined. The challenge of writing about illness is to relay the inexpressible physical pain and to contextualize it within the whole experience of being ill.

How important is it to be able to accurately describe one's pain? Scarry has argued that the impossibility of grasping another's pain has medical implications, but does finding more expressive means provide a solution? Alphonse Daudet's *In the Land of Pain*, a book whose title itself reflects the immensity of his pain, provides some answers to this question. Scarry uses Woolf's claims in *On Being Ill* to reflect on the absence of bodily pain in literature (10-11), yet Daudet's notable effort passes her by, perhaps because it was only translated to English in 2002. Scarry illustrates how descriptions of pain generally fall between two categories. They either require an "external referent," like a weapon even if none exists, or portray bodily damage even if no such damage exists. One of Scarry's apprehensions of using a weapon as a metaphor to describe pain is the way it fortifies the etymological meaning of the word pain, which is "poena" or "punishment" (Scarry 16). Throughout the book Daudet provides a wealth of descriptions that sometimes conform to Scarry's categorizations and sometimes do not:

Varieties of pain.

Sometimes, on the sole of the foot, an incision, a thin one, hair-thin. Or a penknife stabbing away beneath the big toenail. The torture of 'the Boot'. Rats gnawing at the toes with very sharp teeth.

And amid all these woes, the sense of a rocket climbing, climbing up into your skull, and then exploding there as the climax to the show. (21)

In the metaphor of the "rocket," he does not merely use a referent or external object inflicting pain, rather he describes its movement through the body, and how it gradually climbs "up into [the] skull." A rocket, also, cannot be considered a weapon, although the metaphor still ends with the image of an explosion.

At other times Daudet uses personification to describe pain as what it means for a person dealing with it on a daily basis like in the following instances: "the Pain, that cruel guest," (31) and "[a]s if Pain were not already the most despotic and possessive of Imperial hostesses" (42). Despite all his efforts to describe his pain, he is still aware that each person, to use Scarry's analogy further, wanders alone with his pain like a planet amid the vast galaxies that contain perhaps millions of other planets just like himself, in pain, yet never managing to fully embody the other's experience. He writes: "No general theory about pain. Each patient discovers his own, and the nature of pain varies, like a singer's voice, according to the acoustics of the hall" (15). Does his acknowledgment of the variation of each person's experience make such an account more truthful than a general one like Dickinson's? While at the outset it might seem so, the answer is not as easy. In a sparse short poem Dickinson emits a powerful feeling, Daudet's specific account, though important in the way it manages to describe something inexpressible,

sometimes reads like a barrage of symptoms without context.² Despite the rich imagery, they sometimes produce a sensory overload. However, when Daudet writes: "Pain is always new to the sufferer, but loses its originality for those around him. Everyone will get used to it except me" (19), the very fact that his descriptions feel like an overload, reveals the tragedy of the loneliness of bodily suffering.

The comparison between Dickinson's poem to Daudet's notes, address questions on the difference between works that tackle pain through a conceptual lens, and contemplate what pain actually means, and others that delve into the specificity of their pain. While both the poem and the collection of notes, have their differing strengths, Dickinson's evocation of pain is more resonant. However, when discussing the lived-experience of illness as a whole and not only pain, can the answer be as easy? The distinction between universal and specific is in itself fluid, and a single work can wander in and out between the two approaches. Also, one has to be careful of considering a work that depicts a certain affluent class and dominant gender as the "universal." Comparing *The Death of Ivan Ilyich* by Tolstoy to *The Undying* by Anne Boyer will illustrate the difference between both approaches of writing about illness, the universal and the particular, respectively.

Tolstoy's Universal Approach to Death

Soviet critics considered the character of Ivan Ilyich to be "a product of his time and class" (Shcheglov qtd. in Shepherd 401), while non-Soviet critics adopt Robert Russel's view that "[h]aving, through the power of his writing, engaged the reader's attention in the fate of this man, [Tolstoi]³ does everything he can to ensure that the reader perceives this man as Everyman" (qtd. in Shepherd 402). Perhaps both statements are equally true. It is true that Ilyich is a product of his time and place. However, he is depicted so generically that he also becomes an archetypal

character, a man who has spent his entire life trying to conform to societal norms in order to lead a life of decorum and pleasantness. Tolstoy relays a biographical tale, but swooshes through any specific details of Ivan's life. Years pass by in a blur with slight mention of them in short paragraphs. Even moments of utter significance are mentioned in passing, like the following passage: "They moved; they now had little money and his wife didn't like the place to which they had moved. Though his salary was more than it had been, life cost more; also two children died, and so family life became even more unpleasant for Ivan Ilyich" (49). Here, the experience of two children dying comes as an afterthought to the changes that took place in the house, shedding light on how Ivan dealt with life superficially, not letting any real feelings penetrate him.

The second chapter, which is the start of Ivan's biographical tale, begins with the following statement: "Ivan Ilyich's past life had been very simple and ordinary and very awful" (39). This "ordinary" life is emphasized in many instances throughout the novella, as when Tolstoy writes: "everything that all people of a certain type do to be like all people of a certain type" (55); and "that was just like the usual way such people spend their time, just as his drawing room was like all drawing rooms" (58). While this generic social-climbing conforming type of character can be easily identified across different geographical and temporal locations, the universal aspect of this story lies not in the familiarity with such a character, but in its depiction of dying.

When Ivan's health starts deteriorating, a shift occurs. Ivan is no longer a generic character, and tries hard to hold onto his unique identity:

All his life the example of a syllogism he had studied in Kiesewetter's logic—
"Caius is a man, men are mortal, therefore Caius is mortal"—had seemed to him

to be true only in relation to Caius but in no way to himself. There was Caius the man, man in general, but he wasn't Caius and he wasn't man in general, and he had always been something quite, quite special apart from all other beings; he was Vanya, with Mama, with Papa, with Mitya and Volodya, with his toys and the coachman, with Nyanya, then with Katenka, with all the joys, sorrows, passions of childhood, boyhood, youth. (77)

While the outside world gradually diminishes as he becomes more and more isolated, yet more attuned to his inner voice, the story ceases to be about anything but Ivan's close contact with death. He does so by relaying an existential crisis that still deeply resonates with readers more than a century later. The English contemporary novelist Zadie Smith writes, for instance: "[E]very time I read it, I find my world put under an intense, unforgiving microscope" (n.p). While the novella has some very straightforward ideas, like satirizing the idleness and frivolity of the bourgeois class, much of it, especially towards the end remains elusive. Ivan's illness is never given a specific name, and even more disconcerting is the fact that he does not reach an epiphanic moment where he knows how he should have lived instead. Yes, upon his deathbed he sees light and the novel ends on a note that implies he had accepted his death. However, it does not answer Ivan's question after admitting that his life was lived "wrong": "I can, I can do what is right. But what is right?" (105). This elusiveness gives the novel its resounding effect and invariably makes readers turn to themselves.⁴

The Eidetic Features of Illness

Why is it important to find what is universal about illness and what is lost in the process of doing so? Can one even try to encapsulate the experience of illness? S. Kay Toombs, a sufferer of multiple sclerosis, makes such an attempt. In her article, "The Meaning of Illness: A Phenomenological Approach to the Patient-Physician Relationship" (1987), she argues that characterizing some eidetic features of illness may aid patients in their medical experience. What she means by eidetic features are general characteristics that can hold true to most illnesses despite their varying manifestations. These eidetic characteristics include "the perception of loss of wholeness and bodily integrity, loss of certainty and concurrent apprehension or fear, loss of control, loss of freedom to act in a variety of ways, and loss of the hitherto familiar world" (234). She devises these characteristics in order to bring closer the different "worlds" of doctor and patient. While doctors deal primarily with disease and use medical terminology on how to cure it, patients are more concerned with the illness as lived experience.

Toombs actually uses Tolstoy's novella as an example to show the gap between the differing perceptions of doctors and patients to illness. Her ideas on the differing "worlds" of doctors and patients explain why Ivan's encounters with doctors frustrate him more as they give different diagnoses, but never reveal the implications of illness on his life. While these eidetic features may have been helpful at the emergence of the field of Medical Humanities, now they seem outdated and reductive. Like the first wave of medical humanities, Toombs is primarily concerned with the encounter between physician and patient, not paying heed to the social and economic factors. While these features may apply to most patients, their varying degrees affect the illness experience significantly. Toombs has also only highlighted losses, which is important for a physician to acknowledge. Yet only highlighting losses, engenders a more limited view of

illness, one that does include the whole spectrum of an illness experience. Virginia Woolf, for instance, believes that illness releases creative energy. Even in the case of Ivan, the losses while initially experienced negatively, still give Ivan insight into the way his former life was lived wrongly.

In *Phenomenology of Illness*, Havi Carel considers Toombs's work to be "influential" and "a starting point to many later works" (36) that explore illness through phenomenology. However, Toombs's eidetic characteristics still have their critics. According to Carel, critics believe that "the concrete context in which illness is experienced, cannot be stripped away from the experience of illness [. . .] the abstraction of concrete contents of an individual life removes much of what is essential to it" (38). To what extent, then, is *The Death of Ivan Ilyich* abstract? And to what extent does it embody a concrete illness experience? According to Edward Wasiolek's article "Tolstoy's 'The Death of Ivan Ilyich' and Jamesian Fictional Imperatives" (1960-1961), Tolstoy goes to the extreme of trying to convey an idea through story:

By leaving behind the endless qualification of a particular experience, Tolstoy was able to do what is perhaps most distinctive of Russian fiction, to trace out the extreme but logically possible, reaches of a human characteristic. We do not have character represented in the *The Death of Ivan Ilyich* as it presents itself phenomenologically, but as it is theoretically possible in the human condition. (321)

It is true that reading the novella alongside Tolstoy's autobiographical account, *Confession* (1882), shows how the novella is a fictionalized attempt at conveying the existential crisis of Tolstoy. However, what Wasiolek fails to notice is that through its form and its internal monologue that keeps taking dominance as the illness progresses, the novella can also be

considered a phenomenological rendering of illness. In *Tolstoy: A Guide for the Perplexed* (2008), Jeff Love writes: "As several critics have noted, the chapters in [the second part] of the story become shorter and shorter. This tendency reflects how Ivan Ilyich's sense of time begins to change as he comes closer to the realization of the inflexible nature of his illness, its fatal resistance to human manipulation" (96). This reflection on temporal acceleration shows how the form itself embodies the illness experience. It is then reductive to consider that the novella only poses an abstract question, or that it presents a character "as it is theoretically possible." Interestingly, the more Ivan leaves behind his generic life and experiences his own very particular crisis, the more universal the story becomes. Using fiction, Tolstoy's philosophical questions are explored even more deeply and truthfully than in his autobiographical *Confession*.

In *Confession*, Tolstoy poses philosophical questions on what it truly means to live. After trying to find the meaning of life through the teaching and writing of Solomon, Schopenhauer, and Buddha, Tolstoy comes to the conclusion that the life of the peasant is more authentic than the life that he had led, a bourgeois life that prizes rational knowledge. The character of the good-natured peasant Gerasim in *The Death of Ivan Ilyich*, with his more accepting spirit of death, then seems to reflect Tolstoy's own biases. Tolstoy writes in *Confession*:

By contrast with what I saw in our world, where all of life passes in idleness, amusements, and discontent with life, I saw that the whole life of these people [the peasants] passed in heavy labor, and they were less discontented with life than the wealthy. By contrast with people of our world, who resisted and were indignant at fate for privation and suffering, these people accepted illness and sorrows without any bewilderment or resistance but with a calm and firm conviction that all this must be and cannot be otherwise, that this is good. (176)

Through his views in *Confession*, it is then apparent that Gerasim, is used as representation of "the peasant life" that serves as a contrast to the bourgeois life depicted in the story, rather than a fully-fleshed out character. To think "these people," the peasants, accept illness and death more readily than people of the bourgeois class, does not elevate the status of peasants, as perhaps Tolstoy had intended, rather, it undermines their suffering. Yet the difference between this statement in his autobiographical text *Confession*, and the novella's depiction, is that despite the dichotomy presented, the novella still remains elusive. It is true that the novella is imbued with dichotomies, like authentic/inauthentic, right/wrong, bourgeois/peasant, which give the story a parable-like undertone, despite its realist manner. However, because of the intensity of Ivan's internal monologue and his inability to find "the" answer, the dichotomies are transformed from reductive tropes to contrasts that make Ivan's crisis more horrible. It is then impossible to categorize the story as either abstract and universal, or specific and phenomenological. One can say that the novel is a realistic parable set in elite social life of nineteenth-century Russia. Yet this still does not give it justice. A more accurate description would be to say that the novella is about Illness and Death and includes the particular circumstances of the life of a man, only to accentuate these abstract concepts and make them felt.

While abstract thought on the "condition of man" can sometimes be limited, this "general idea" can still be used to apply to varying specific situations. A less horrific and more poignant loose adaptation of Tolstoy's novella is Akira Kurosawa's 1952 film *Ikiru* (To Live). While it relays a completely different story, it still uses the same abstract ideas and questions of *The Death of Ivan Ilyich*. The story follows a man diagnosed with terminal cancer, and his quest to find meaning to his life. It shows that the dichotomy between living/not fully living does not have to apply to the frivolous existence of the bourgeois class with their attachment to material

luxuries against a more meaningful life, but that not really living can also apply to a bureaucratic man, having to pass his days "doing nothing at all" in the bureaucratic machine, despite his apparent busyness. Unlike, *The Death of Ivan Ilyich*, the film has a redeeming quality, as its protagonist, Kanji Watanabe, has more time to find his own meaning. What is interesting about the film, is that the meaning he arrives at is not some grand philosophical concept, although implicitly it can be read that way. What Watanabe does at the end is use this same bureaucratic tool to build a children's park, after turning down a group of mothers pleading for one at the beginning of the film. This seemingly simple act says a lot about his transformation. It shows how his own transcendence was reached through the transcendence of his own egoistical desires, or perhaps better said, his apathy towards others. Ivan similarly accepts death when he starts thinking of how his illness is affecting his family.

When a Literary Trope Conceals Inequality

A short story by the Egyptian writer Yusuf Idris titled "Lughat al-ayay," (1965) also draws upon similar themes as *The Death of Ivan Ilyich*, yet with less intensity, perhaps because it is not the protagonist himself who is in pain. The title, which means "The Language of Ayay [a cry of pain]," depicts a bourgeois family hosting a sick peasant, a former friend of the protagonist in the story. The story depicts the protagonist's wife as evading any presence of suffering. Like Ivan's wife, who could not bear to listen to his cries of pain "from three doors away" (*Death* 36), the wife in Idris's story probes her husband to get rid of his friend after every squeal of pain. The difficulty of describing pain is again evident in this story when Idris writes: "He was not surprised when the doctor told him that in a situation like this, a painkiller rarely eases the pain. The pain of this type of cancer is far stronger than all drugs and painkillers invented by the human race" (8). Towards the end of the story the man, like Ivan, but this time

not because of his own suffering rather than that of his friend, reassesses his whole life. He remembers his own childhood in the village and is aware of the falsity of the life he had led afterwards, living in an affluent neighborhood and working to garner prestige. While idealizing village life is a common trope in the realist setting of Tolstoy's novella, romanticizing Gerasim, the caretaker of Ivan who has to take out his excretion among other difficult tasks, fails to acknowledge the inequality of the situation.

It is true that Tolstoy was a staunch opponent of private property and has fought throughout his life for social equality. Yet biographical facts aside, in order not to conflate the fiction of Tolstoy with his own life, the depiction of Gerasim as the man who would do these tasks of care "easily, willingly, simply, and with a goodness of heart" (84) is a glaring example of the inequalities inherent in the work of care. The depiction of Gerasim as an ideal has in its core an exploitative sentiment, a sentiment that is not particular to Tolstoy's novella, but an issue that persists until this day. There is a general assumption that the labor of care has to be done out of good-heart and without much expectation for monetary return.

Laura Anne Robertson, a trainee nurse in the UK, begins an article titled "Who Cares" (2014) on the inequality in the work of care, with a telling anecdote. She writes that during an interview for a mental health nursing program, she was asked how she would deal with the situation of a patient wetting themselves at the end of her shift. Because she was in an interview, she answered "correctly" that she would of course clean them. Robertson ends the anecdote with the following statement: "Wannabe nurses must demonstrate their compassion. And compassion, we are taught, means cleaning shit for free" (32). The article criticizes the way that nursing has been so interlinked with compassion, that a nurse has to constantly show it at the expense of her own wellbeing and even at times at that of her own family's. Robertson writes that love and guilt

is inherent in the domestic work of care largely done by females, and the same mechanism is used in the female workforce of care to justify the low wages and long working hours. Robertson does not propose solutions in which love is completely taken out of the equation in the work of care. She highlights the demands of "the International Wages for Housework Campaign [which include] a substantially reduced working week, a guaranteed income for all (women and men) and free community-controlled childcare" (33). If such demands are met, perhaps love would still exist in work of care, but without exploitation.

Boyer's Particular Cancer Experience and the Politics of Care

The poet Anne Boyer, who wrote about her breast cancer experience in *The Undying*, reflects extensively on the politics of care. Upon reading Thomas Mann's *The Magic Mountain* (1924), Boyer writes in an article for Full Stop (2015): "The Magic Mountain's sick time is achingly bourgeois in the 'unavailable' sense of that word. If only there were luxurious alpine chemo-spas full of philosophizers for any of the twenty-first century league of the working-class ill to afford. There aren't compliant someones to bore us with regular nourishment: this is because we are those someones" (n.p). Boyer, while on chemotherapy, had to continue working and taking care of her daughter, which makes such narratives—of the bourgeois ill—somewhat irrelevant to her experience, despite the universality of some of their aspects. Boyer is well aware that "[c]ancer is not a sameness eternalized in an ahistorical body, moving through a trajectory of advancing technological progress" (30), and throughout the memoir she tries to make sense of what it means to have breast cancer in the contemporary world. She takes into account issues relating to the society at large and writes about her illness not as a personal crisis in a vacuum, but rather as a result of our hyper-consumerist hyper-capitalist era at the brink of an ecological crisis.

In one of the interesting sections of the book, Boyer reflects on the politics of care through the act of washing the dishes. She begins this section as follows: "Doing the dishes is not like freedom. Freedom is whatever we notice because it isn't like doing the dishes. The ordinary is ordinary because it ordinarily repeats: taking care lacks freedom's entertainments and its exceptions" (107). In this book, like in her poetry collection Garments Against Women, Boyer takes the daily unnoticed acts of labor mostly done by women, like doing the dishes in The Undying and sewing in Garments Against Women and puts them in the foreground. These tasks despite their unremarkable nature, because they take a large chunk of her day and of the many unnoticed workers, make their way into her art instead of being underwritten as moments unworthy of attention. She tries to imagine what it would be like to produce narrative through washing the dishes, perhaps a story about what is being missed out while doing the dishes, or "a stream of consciousness account of an attempt to flee dish-sink reality" (107). Either way the act itself will not "produce narrative" because "it is not interesting or remarkable work in itself, but it is the work on which everything else depends" (107).

Equally unremarkable, can be the endless days spent in bed, a hospital or infusion room. However, in acknowledging them, one also acknowledges how one can preserve their humanity beyond "economic" activity. In an article on Boyer's poetry collection, *Garments Against Women*, as well as the poetry collection by Elizabeth Arnold titled *The Reef*, Sarah Nance puts illness and the unpaid work of care in a category called: "alternative economy." What illness and unpaid care work have in common is that they take place outside the productive capital economy and are "unnoticed and thus un(der)valued" (167). Nance then borrows another term which is "affective economy," which has been explored by scholars in different ways to acknowledge the labor that is produced outside the economic structure. Nance, however, uses the term in her

article to specifically explore chronic illness and its relation to the economy. Nance writes: "For the women in this essay, poetry offers a means of producing an alternative representation of illness that does *not* feed back into the temporal cycles of a capitalist economy, even as those capitalist cycles exist in their experiences" (175). Nance considers the act of writing poetry, and more specifically poetry about illness and pain, to be a subversive act. She quotes the following statement by Magdalena Zurawski:

But the poem is not a form of money. The poet is a form of money, as my paycheck from the university tells me every month. But what about the poem that tasks itself with the refusal of work? What about the poem that loafs and loiters and emerges from the mouth of someone for whom it is criminal to loaf and loiter? In a world that continually limits the definition of the human being to economic functions, the poem serves as a reminder of a being that we have within us that is otherwise. (qtd. in Nance 180)

Zurawski's ideas point to Virginia Woolf's reflections in her essay *On Being Ill*, when she writes that the ill are "deserters" of "the army of the upright" (12). Zurawski and Woolf use words like "loafing and loitering" and "desertion" in a way that turns their negative connotations into a more positive one. Zurawski's description of "loafing and loitering" as "criminal" can be considered as a writer's overstatement for emphasis. Yet, one has to only look at Boyer's situation, in which she had to work all through her chemotherapy, and have her friends carry her books for her at work, to know that in contemporary America, sometimes it is not even allowed to be ill.

When the Specific Engages with the Universal

In *The Undying* Boyer contemplates upon her specific condition, yet she is constantly in dialogue with the large tradition of writings on illness, cancer in general, and breast cancer in particular. Her prologue relays how writers before her, like Susan Sontag, Audre Lorde, and Frances Burney, among others, have dealt with having breast cancer in their writing. She uses literary and historical allusions and appropriates them to her own condition. Her first section "The Incubants," refers to the incubants in ancient Rome, who lived in the temple of Asclepius to receive remedy advice in their dreams. She later writes: "A newly diagnosed person with access to the Internet is Information's incubant" (21). In the contemporary world, the dreams of the incubants are replaced with the internet, numbers and statistics. Boyer does a lot of play on words and titles. Her second section "Birth of the Pavilion" refers to Foucault's *The Birth of the Clinic*, and throughout the book she invents different titles for well-known works like *Neutropenia in the Time of Enterovirus*, to describe her diminishing immune-system, and *The Medically Induced Failure of the Remembrance of Things Past* to refer to her memory loss caused by chemotherapy.

However, she does not only use these titles to play on words, but to also offer commentary. When she writes for instance: "Real literature would be *Proust in Bed*, about an affluent man who is deeply interested in his mother," (144) she refers to her earlier statement that "[o]nly certain kinds of sick people make it into art" (104). This is followed by examples of the people that have been left out of art's representation: "I've never seen a painting of an incarcerated woman sick from breast cancer hanging on the wall of the Louvre. I've never seen a sick person in a car in a rural emergency room parking lot on the walls of the Met" (106). These statements by Boyer again reveal the inadequacy of a theory like Toombs's which

compartmentalizes illness characteristics. The specific conditions of illness are what makes an ill person marginalized and underrepresented, and another not. Boyer also points to the question of what we deem as real literature, and undermines it. The canonized Proust is then turned into "an affluent man who is deeply interested in his mother." As a statement it makes the critique on canonization more powerful, yet it also endangers the view that any work of a socially privileged person is of no value. Proust's prose and deep engagement with the inner world and his depiction of the flights of memory cannot be summarized as only the literature of a man interested in his mother. A more encompassing, yet critical view on illness and privilege is Audre Lorde's diary entry in A Burst of Light on the film Terms of Endearment, in which a woman dies from cancer. Aware of the "taken for granted" privilege of the white affluent characters, and commenting on how there are no Black characters anywhere in the hospital, Lorde is still touched by the film. She writes: "Now this may not make her death scenes any less touching, but it did strengthen my resolve to talk about my experiences with cancer as a Black woman" (73). Rather than undermining the literature of Proust only because of his affluent status, it is then more important to try to encompass more voices, and critique the concept of valorization.

However, Boyer's engagement with earlier work on illness does not always come from a place of criticism. In several instances, she uses earlier works on illness to find a point of contact, a shared truth. This shows that even in her attempt to write about her very specific situation, she still taps onto the universal. Her reflections of the sickbed, in which she uses a metaphor by John Donne, can find resonance in the poetry of Amal Dunqul. Boyer writes: "There is no more tragic piece of furniture than a bed, how it falls quickly from the place we make love to the place we might die in" (95). She then refers to John Donne's metaphor of the bed as a grave, which comes from the following passage in *Devotions Upon Emergent Occasions*: "A sicke bed, is a grave;

and all that the patient saies there, is but a varying of his owne *Epitaph*. Every nights bed is a *Type* of the *grave*: At night wee tell our servants at what houre wee will rise; here we cannot tell our selves, at what day, what week, what moneth" (4). Amal Dunqul in his poem "Al Sarir" ("The Bed") similarly contemplates on how the sickbed is a kind of a grave. Dunqul ponders upon the permanence of hospital beds and the ephemerality of the people who inhabit it. The poem is about the narrator falsely thinking that the hospital bed is his, and how in his state of repose, the bed itself thinks that they are one body. When the bed notices that there is a foreign body on it, it tells the narrator how it does not favor any person over another. It ends with the equally tragic and hopeful lines: "And those who sleep will eventually leave/ to swim towards the river of life/ or drown in the river of silence" (401).⁷

The horizontal position of lying down, is one that connects all those who are ill, the same way that "the cancer pavilion is a cruel democracy of appearance" (Boyer, *The Undying* 49). Yet while Donne believes that the erect position of man is what brings him closer "to the contemplation of *Heaven*" (4), Boyer takes this thought and reverses it. She does not believe that lying down is a position away from heaven, rather:

In vertical life, when you are well or mostly and walking around, pretending to be, the top of your head is the space that heavens touch. The total area of the top of you is pretty small. You are only moderately airy, then, and your eyes, rather than gazing up, gaze outward at the active world, and it is to this you are mostly reacting [. . .]. When you are sick and horizontal, the sky or skyish air of what is above you spreads all over your body, the increased area of airy intersection leads to a crisis of excessive imagining. All that horizontality invites a massive

projecting of cognitive forms. When you are often lying down, you are also so often looking up. (95-96)

Boyer's passage is a continuation of Virginia Woolf's ideas in *On Being Ill*, in which an ill person is finally able "for the first time for years, to look round, to look up--to look, for example, at the sky" (12) and how that releases creative energy. While Boyer could be alluding to Woolf, what both writers suggest is that the ill state, precisely because it forces the ill to a state of repose invites a flood of perceptions, not otherwise attainable when being active and looking forward rather than upward. The similarities between the passages again reflect the universality of some aspects of illness. Even in a narrative that is harsh and bleak like Boyer's, Woolf's romantic idea of the expansion of the inner world is evoked.

Despite the specificity of the situation of an ill person, there is still a shared world of all those who have suffered from and contemplated illness. Writing from this position is what Arthur Frank has termed as "the act of witness," in which testimony allows one to be "in love with the humanity that shares sickness as its most fundamental commonality" (40). This can be seen in the way Boyer, in her attempt to evade the tedious and unhelpful numerical metric of pain (1-10), turns to the poetry of Dickinson for its acute and often accurate descriptions of pain. In order to write about illness, then, one has to tap into the universal and specific, no matter which position is initially taken. Illness is one of the most personal of experiences and can completely alter a person's life, but it is also universal, and always political. To write about illness, one has to keep on pulling different threads simultaneously and doing so invites forms of writing that also elude categorization, and that can fluidly move from one genre to the other. Tolstoy's novella, then, is both a realist story and a parable. Anne Boyer's book is even more difficult to categorize: it mostly oscillates between the genres of memoir and essay, but it also

has passages of philosophical reflection, and some full of anger that can be considered a manifesto for women battling breast cancer. Rather than viewing the universal and the specific as two opposing approaches, maybe it is then better to consider them as complementary.

Chapter 2

The Amalgamation of Genres as a Disruption of Cancer's Metanarrative

While inventions in the medical field, such as penicillin, have saved numerous lives and contributed to better health and longevity, modern medicine has created new challenges—what Arthur Frank calls "the remission society"—which encompasses all the people still suffering from the repercussions of earlier, not completely cured, illnesses (8). Cancer, one of the most vicious killers in our contemporary world, is a disease whose cure can sometimes just mean extending a life of suffering. Even breast cancer, which according to Barbara Ehrenreich is now perceived through the lens of "positivity" as a "rite of passage [. . .] a normal marker in the life cycle, like menopause or grandmotherhood" (29), still kills around 271,245 women annually ("WHO"). According to a 2019 statistics report by the American Cancer Society, breast cancer "is the second leading cause of cancer death among women after lung cancer" in the U.S. (438). Globally, it has the highest rate of cancer death in more than 100 countries ("Global Cancer" 412). To survive breast cancer, patients still have to suffer from either mastectomies, lumpectomies or the tormenting consequences of chemotherapy. While early detection has indeed helped in reducing mortality rates "it still does not guarantee a total cure.

To be critical of the upward trajectory of progress, one has to also look at the way illness is dealt with beyond cure. How is the sick person cared for—and how does the healthcare system and the community aid patients in their experience—can indicate if there is any "progress" made. Anne Boyer in *The Undying* offers the following lament on what she calls "drive-by mastectomies," in which "the patient is forced onto her feet and out of bed"¹⁰ (156):

In the 1970s, Audre Lorde, according to *The Cancer Journals*, spent five days in the hospital being cared for after the removal of one of her breasts [. . .] . Despite the lie of progress, so many people with breast cancer don't get any of this anymore, nor adequate pain control on leaving surgery, nor physical therapy for postmastectomy pain and mobility issues, nor time off work, nor is the loss of a breast nearly their biggest postcancer problem [. . .] . When reading historical accounts of breast cancer, I am often struck by a world on which profit hadn't taken such a full and festering hold. (155-156)¹¹

Boyer's observations on progress, which mostly talk back to Siddhartha Mukherjee's 2010 book *The Emperor of All Maladies*, are important. However, scientific progress still cannot be undermined. The survival of children dying tragically of leukemia, relayed in Mukherjee's book, is a triumph despite the problems of modern healthcare. To discuss this issue, it is then wiser to consider the importance of the upward trajectory of science, yet still be critical of it.¹²

A Brief History of Breast Cancer

How was breast cancer dealt with throughout history and how has the conception of it as a disease evolved? While many consider cancer to be a modern disease, historical accounts indicate that it has been present perhaps since ancient times. According to Mukherjee, a papyrus from ancient Egypt assumed to be written by the physician and "Renaissance man" Imhotep indicates that what appears to be breast cancer existed even then: "Bulging tumors of the breast mean the existence of swellings on the breast, 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" (qtd. in Mukherjee 40). In the Papyrus, Imhotep admits that as for therapy: "There is none" (41).

Sarah E. Owens also traces writings on breast cancer in Early Modern Europe in her (2012) article "The Cloister as Therapeutic Space: Breast Cancer Narratives in the Early Modern World." While most archival documents were written by medical practitioners, she uses two accounts written by nuns, to paint a picture of the way breast cancer was dealt with and shows how the convent provided a healing place that allowed an ailing nun complete bed rest and comforting care from fellow nuns. Contrasting Anne Boyer's "profit's festering hold" is perhaps this account of Madre María Rosa in *Journey of Five Capuchin Nuns* (ca. 1712). She describes a new infirmary in a convent in Lima: "It is the most comfortable workplace in the convent. Because it was constructed with our input, every last detail was added, not only to care for the ill sisters, but also for the nurses. It has a very beautiful main room with an altar on the main façade" (qtd. in Owens 328). However, what Owens describes is only life inside the convent, and cannot be used as an example of the medical care in general in Early Modern Europe. Also, while the convent inspires a healthcare ideal that takes into account the psychological, and spiritual aspect of the ill, one cannot completely demonize modern healthcare.

While mastectomies are until this day harrowing procedures, the emergence of the anesthetic, for instance, has reduced the traumatic moment of feeling every single pain, as the surgeon is cutting up the breast. An account of the intensity of an unanesthetized mastectomy is relayed by Frances Burney in 1811, perhaps the first written account of a mastectomy in history. In a letter to her sister, Burney describes the experience:

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--& I almost marvel that it rings not in my Ears still! so excruciating was the agony. When the wound was made, & 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 & forked poniards, that were tearing the edges of the wound [. . .]. I attempted no more to open my Eyes,--they felt as if hermetically shut, & so firmly closed, that the Eyelids seemed indented into the Cheeks. (138-139)

What is different in this quote than others describing pain, like Daudet's for instance, is that the external weapon exists in reality. Burney describes the motion of the knife, by listing all the body parts that are cut. Burney's wound is visible, as is her pain when she describes her own face and how her "Eyelids seemed indented into the Cheeks" to reflect the immensity of pain. This visible pain, gives off a cinematic effect—the one in which a viewer winces at the sight of a knife approaching flesh. This again points to the tragic conclusion that pain has to be visible in order to be felt by others.

Yet Burney's vivid, minute description of every sensation with the contact of the surgeon's knife is not only important for being able to transmit the feeling of pain. It is also important in resisting the dominant sexism in the medical field, when compared to the statement of this eighteenth-century German physician Lorenz Heister:

Many females can stand the operation with the greatest courage and without hardly moaning at all. Others, however, make such a clamor that they may dishearten even the most undaunted surgeon and hinder the operation. To perform

the operation, the surgeon should be steadfast and not allow himself to be discomforted by the cries f the patient. (qtd. in Mukherjee 49)¹³

Additionally, it draws attention to the way this early nineteenth-century account provides such a raw description of the experience, something which is largely missing in contemporary

America's climate of "breast cancer positivity."

Disruptive Breast Cancer Narratives

Continuing Burney's tradition of writing an unadorned account about breast cancer, Anne Boyer's book The Undying proclaims: "I do not want to tell the story of cancer in the way I have been taught to tell it" (115). The book, while not an isolated voice, talks back to the way the accepted story of breast cancer has become a story of positivity and triumph. Critics of the current trend in breast cancer positivity are many, including Barbara Ehrenreich in her 2009 book Bright-Sided, and Diane Price Herndl in her 2006 article "Our Breasts, Our Selves." The documentary film *Pink Ribbons, Inc.* (2011) delves into the hypocrisy of the Pink Ribbon Foundation, and shines a light on how companies use the campaign to promote beauty products that contain carcinogenic chemicals. Even in the 1980s when Audre Lorde wrote *The Cancer* Journals, signs of the way this disease is currently dealt with were already apparent. In her last section of *The Cancer Journals*, "Breast Cancer: Power Vs. Prosthesis" she relays how The Reach for Recovery program insisted that she wear prosthetics for the morale of other patients. Lorde could not comprehend the sexist worry that a partner would find her less attractive with one breast, and writes: "A lifetime of loving women had taught me that when women love each other, physical change does not alter that love" (57). Instead of concentrating on the "cosmetic" aspect of the mastectomy, Lorde considers the emotional aspect of the experience. She writes: "Any woman who has had a breast removed because of cancer knows she does not feel the same."

But we are allowed no psychic time or space to examine what our true feelings are, to make them our own. With quick cosmetic reassurance, we are told that our feelings are not important, our appearance is all, the sum total of self" (58). Throughout her book, Lorde instead questions how she should deal with her new identity, her new situation, and how to incorporate her cancer experience in her larger work of activism.

Kirsten E. Gardner in "Disruption and Cancer Narratives: From Awareness to Advocacy" (2009) analyzes three works by Rose Kushner, Audre Lorde, and Gabriela Arredondo that present a more nuanced breast cancer story than the propagated "metanarrative" about early detection and eventual cure. Gardner chronicles the evolution of the American Society for the Control of Cancer (ASCC) later becoming American Cancer Society (ACS), and examines the early formation of the breast cancer "metanarrative" and its failings. While the initial purpose of these stories created by the ASCC has contributed to awareness about early detection, it has also written off many stories, especially those by women of color and working class women who cannot afford to easily get tested. In addition, these polished stories, do not reveal the full-extent of the gravity of a breast cancer experience. Gardner asks:

Where do women encounter narratives about caregivers who hold the shoulders of patients vomiting violently after a round of chemo? Or about bathing the breast cancer patient who is too weak to wash herself? Or about caregivers who trade secrets in the waiting room about easing the pain? [. . .]. Or, for that matter, where are the narratives communicating the kind of suffering that Burney felt? (Gardner 335)

The campaign of the ASCC, which has targeted different media outlets, from ads in bus terminals to film and television, had but one clear message: "Get detected early and you will

survive." The general approach of the ASCC was to address the issue of a woman's (usually white and middle-class) fear of getting tested, not paying heed to the economic situation of the breast cancer sufferer. The three works that Gardner delves into present a variety of stories that "disrupt" this metanarrative. While Gardner believes that these multi-layered cancer stories have become more prevalent since the initial publication of the feminist manual *Our Bodies*,

Ourselves in 1970 by the Boston Women's Health Collective (BWHC), the "metanarrative" of detection and cure is still dominant in breast cancer discourse, and critical voices still pale in comparison.

In *The Undying*, Boyer is not only critical of this "metanarrative"; she constantly examines the different ways one can actually capture the experience of illness. In a section explaining why she is writing this memoir, Boyer cites Bertold Brecht: "But the truth cannot merely be written; it must be written for someone, someone who can do something with it" (134). She interjects Brecht's quote with a litany that constantly repeats the statement, "I would rather write about anything else," following it with a different answer each time. While the first two proclamations reveal her apprehension to write yet another cancer story, the concluding third statement admits that "other people exist, all of us with environments and hours and desires, like the one to not be sick, or to not get sick, or to understand what it means when we are" (134). This conflict of whether or not to write this book is reflected throughout the book, and in a sort of conundrum it is actually the force that is driving it forward. Boyer's style, of writing about something through not writing about it, has been recurrent throughout her previous work as well. Lindsay Turner, through a close-reading of Boyer's poetry collection Garments Against Women, defines Boyer's approach as paralipsis. Turner writes: "A key premise in Boyer's poetry, though, is that she writes about such matters largely by not writing about them. She does so, in other

words, by deploying or riffing on the rhetorical figure of paralipsis: stating something through the claim not to be stating it" (122). Boyer then is forging a literary style that is built on paradox. The categorization of the book itself is contradictory. While at heart a memoir, *The Undying* constantly evades writing about the cancer experience and constantly points out to the memoir's ineffectuality of expression. Boyer's own cancer story is dispersed throughout, told in scattered glimpses. Yet this evasion in itself is conveying something, which is the inexpressibility of the breast cancer experience. At the end one can describe *The Undying* as an "anti-memoir" memoir. This gap-filled reconstruction of Boyer's experience reveals that there is no intention to relay the experience as it happened, as opposed to more linear memoirs, that can deceptively imply that they are sharing "the truth" of the experience. Perhaps no narrative will give justice to an illness experience, or maybe even a life experience? However, all we can do is devise forms that can capture something about it or make sense of what seems meaningless.

Susan Sontag's well-known oeuvre on suffering encapsulates the question of form and illness. In her book *Illness as Narrative*, Ann Jurecic provides an overview of Sontag's conflicting ideas around the portrayal of suffering, and how this very confusion is reflected in her varying choices of genre throughout her career. Jurecic is generally concerned with the split between literary criticism's detachment from illness memoirs, sometimes to the extent of calling them "victim art," and the utilitarian function of illness memoirs as a therapeutic tool, mostly in the field of medical humanism (*Illness as Narrative* and "Empathy and the Critic"). Her example of Sontag reflects these debates, and also shows their complexity: taking either side will result in a narrow understanding of writing on illness. According to Jurecic, Sontag uses the critical essay form in the 1970s and 1980s as a tool to decry false sentimentality. While she turns to historical fiction in the 1990s, she still decides to forego narrative when she decides to write about her

cancer. What she does, instead, is write *Illness as Metaphor*, a work of criticism on the representation of illness. Later, in *AIDS and its Metaphors* (1989) Sontag reflects on her decision not to write a memoir about her cancer experience: "A narrative, it seemed to me, would be less useful than an idea" (qtd. in Jurecic *Illness* 72). However, this is not Sontag's last statement on form. In a 2004 speech she considers "fiction [to be] better suited than the essay for shaping moral understanding." (Sontag qtd. in Jurecic *Illness* 76). This summary of Jurecic's break-down of Sontag's genre shifts reflects the interconnectedness of form and writing on illness, and poses questions on the importance of genre. It does not imply that there is a form more suited for writing about illness, but that illness brings to light what different genres can achieve. Rather that choosing a form of expression, blending different forms enables a writer to use the best form at a given moment.

On Illness and Form

Boyer reflects that "breast cancer is a disease that presents itself as a disordering question of form" (*Undying* 7). Yet, how does form play a role in writing about illness? In "The Illness Essay," Ann Jurecic argues how the personal essay of illness should be given more attention. For Jurecic, the memoir is a product of our neoliberal age, and in a sentiment similar to Boyer's on the straightforward memoir, she writes: "A neoliberal mind-set isolates people from communities of care and can not only exempt them from feeling responsibility to others, but can make them suspicious of others" (18). The "breast cancer positivity" memoirs, with their concentration on the personal journey, disregard the communal aspect of the disease. Herndl in "Our Breasts, Our Selves" (2006) compares different narratives about surviving breast cancer to again ask questions about the link of breast cancer narratives to community. She adheres to Lorde's viewpoint that writing about illness is an ethical act and how it should turn outward to tackle pressing social and

political questions. Yet the link between personal and communal is not the only strength of the essay as a form. Initiated by Montaigne, the essay form relies on posing questions rather than giving answers. This can help investigate the difficult questions on illness, without the need to provide closure or epiphany.

While the essay defies categorization, scholars have still tried to give the essay some characteristics. Lydia Fakundiny in *The Art of the Essay* (1991) likens writing an essay to idling: "Rambling and wandering create and imagery of aimless, uneven, unregulated movement; the leisurely pace, in them, can dilate into something very much like idling" (15). In Virginia Woolf's Essayism (2012), Randi Saloman, argues for the importance of the essay and how its artfulness lies in its process-oriented nature. Looking at Woolf's essays specifically, Saloman argues they should be considered literary works on their own, and not as complementary works that "glean insight into Woolf's own novels," which is how critics generally tackle her essays (48). Saloman writes: "The essay's intrinsic 'shapelessness' or lack of structure means that only the process itself can guide the essayist's journey. It also means that essayists necessarily invest themselves in their work to a greater degree than they may intend or realise, revealing aspects of themselves in the most basic choices they make in organising their attempts" (49). And again she reflects that "[t]he essayist literally reveals the development of an individual mind in real time" (50). While these works of criticism shed light on how the essay allows writers the freedom to explore and go beyond the confinement of the "closed" narrative of the memoir, one cannot simply say that in the essay lies the answer of genre and illness. For one, the essay itself cannot be considered a monolith. There are several types of essay styles, and Sontag's essays differ greatly from the essays by Boyer and Lorde. Sontag wrote her essays as conceptual problems to be solved, ridding them of the emotional experience that she sought at the end of her writing

career. While Sontag generally maintained that the mind and emotions cannot be separated, her oeuvre suggests otherwise (Jurecic, *Illness as Narrative* 73). The use of the essay by Lorde and Boyer—their amalgamation of genres and seamless transitions from the emotional to the critical—open up a space to write about illness, while transcending the dichotomy that Sontag was stuck with.

Embracing the Sentimental

While, like Sontag, Boyer is critical of false sentimentalism, especially the propagated neo-liberal type that emanates positivity; unlike Sontag, she is not afraid to express her emotions, and even revel in what some might deem as melodramatic. The way Boyer evades writing a memoir and uses sarcasm to reflect on her experience, makes Boyer's book in many instances one seemingly conforming to what Leslie Jamison calls the "post-wounded" voice. Jamison in her 2014 treatise "Grand Unified Theory of Female Pain" that urges women to embrace the sentimental, and ends with the following passionate plea:

The wounded woman gets called a stereotype, and sometimes she is. But sometimes she's just true. I think the possibility of fetishizing pain is no reason to stop representing it. Pain that gets performed is still pain. Pain turned trite is still pain. I think the charges of cliché and performance offer our closed hearts too many alibis, and I want our hearts to be open. I just wrote that. I want our hearts to be open. I mean it. (128)

In a similar vein, Boyer embraces the melodramatic to the extent that she fashions a religion around sharing pain. In a section titled "In the Temple of Guiletta Masina's Tears," she imagines a temple in which people congregate to cry in public. In alignment with Jamison she writes:

"When planning the temple, I remembered the existence of people who have hated those they call *crybabies*, how they might respond with rage to a public place in which crying strangers gathered en masse to cry about whatever they liked." (*Undying* 205) Boyer then ends her section with: "I've just always hated it when anyone suffers alone" (206).

While Boyer, wary, still reflects on her personal experience and relays her suffering, Lorde, not only in *The Cancer Journals*, but throughout her work and even her criticism, is guided by her emotional experience. In her 1985 essay "Poetry is not a Luxury," Lorde identifies a poetic voice that has been long suppressed. Her quest is to find that emotional core that links her to an "ancient, non-european consciousness," (37) a consciousness that follows "the Black mother" rather than "the white fathers" (38). She writes:

These places of possibility within ourselves are dark because they are ancient and hidden; they have survived and grown strong through that darkness. Within these deep places, each one of us holds an incredible reserve of creativity and power, of unexamined and unrecorded emotion and feeling. The woman's place of power within each of us is neither white nor surface; it is dark, it is ancient, and it is deep. (36-37)

Similarly, in "Uses of the Erotic," (1978) she believes that there is a tradition of the erotic that should be sustained outside the racist, patriarchal tradition that conflates the erotic with the pornographic. She considers the erotic in its broadest meaning, as using sensuality and pleasure in everyday activities, and considers how emotions and the political can, and indeed should, emanate from the same place. Her poetry, memoirs and essays are inextricably linked with her sensual experiences, sexual and otherwise.

Sensuality informs Lorde's political stance, when she admonishes the usage of prothesis for cosmetic reasons and ponders about losing her breast as a loss of pleasure. Even when her breast cancer metastasizes and she approaches death, Lorde maintains her stance for the sensual. In A Burst of Light, published eight years after The Cancer Journals, Lorde recounts her experience with liver cancer. It is a more resigned and personal account than The Cancer Journals and includes many sections on her own healing or coping process and daily exercises she does to alleviate her pain and suffering. She recounts how she decided to avoid treatments that prolonged her life, and instead took the decision to live her remaining days fully. In its Epilogue she writes:

This is my life. Each hour is a possibility not to be banked. These days are not a preparation for living, some necessary but essentially extraneously divergence from the main course of my living. They are my life. The feeling of the bedsheet against my heels as I wake to the sound of crickets and bananaquits in Judith's fancy [...] It's about trying to know who I am wherever I am. It's not as if I'm in a struggle over here while someplace else, over there, real life is waiting for me to begin living it again. (77-78)

Lorde knows how to accentuate moments of daily life through rich sensory descriptions, like in *Zami*, when the simple act of grinding spices in her childhood is turned from a chore to something more akin to a rhythmic dance (71-80). It is interesting that even towards the end of her life she is still undeterred, and understands that her ill state is not a "divergence," but part of life itself, and that to be able to feel the bedsheets and hear crickets is in itself living.

Lorde's voices vary in *The Cancer Journals* and alternate between the personal and the political. However, these genre and tonal shifts are divided into clear sections. She begins the book with an introduction, and a few journal entries. The book is then divided into three sections. The first is a speech titled "The Transformation of Silence into Action" originally given in 1977. Because of its nature as a speech, she continually addresses the reader in the second person and the plural "we." Starting the book with this speech is an interesting choice, because from the beginning she situates the reader as a witness and fellow collaborator with a responsibility towards the issue to be addressed. The second section, titled "Breast Cancer: A Black Lesbian Feminist Experience," moves again to the personal through diary entries, giving her story immediacy. Diary entries have a similar function to the essay, as a writer has no preconceived idea on how it will turn out. The third section is a manifesto for breast cancer patients against cosmetic prosthesis and what it entails, titled "Breast Cancer: Power Vs. Prosthesis." These different approaches combined show how capturing illness requires alternating forms and voices. The immediacy of all three forms: speech, diary, and manifesto, especially the forms of speech and manifesto that address the reader directly, can indicate why this text has gained such an iconic status.

Much has changed in the breast cancer climate since Lorde wrote *The Cancer Journals* in 1980. Instead of the dearth, there is now a saturation of writings on cancer. However, some things remain the same, such as the toning down of environmental causes in breast cancer discourse. Lorde's optimism about the prevalence of less severe treatments has also been disappointing. Issues of race are glaring as the mortality rate of black women exceeds that of white women by 40%. According to Olivia Banner in "Structural Racism in the Medical Humanities" (2016), it does not fare much better in scholarship on Medical Humanities. She

writes: "Literature and Medicine contained no articles that considered race [since 2009] [...]. The Journal of Medical Humanities evinced a greater interest in race in the United States context: 7 of 134 articles since 2009 concern either writers of color or questions of race/ethnicity in medicine" (28). Reading Audre Lorde's text along with Boyer's gives a glimpse of what has changed and what has remained the same in the discourse on breast cancer. Lorde has set up a precedent of writing an equally angry and personal book about breast cancer, a book that is part life writing and part activism. Boyer's book can be considered a continuation of what Lorde has begun.

Illness as a Form of Protest

Despite the different climates they were writing in, Lorde and Boyer then still share a lot of commonalities. One feature that connects both works is their underlying anger. Both can be considered manifestoes for women trying to cope, recover, heal, or deal with the experience of breast cancer outside the dominant discourse. They also instigate action, rather than try to inspire empathy in readers. In accordance with Sontag's argument that cancer metaphors generally put blame on the patients themselves, Lorde and Boyer know where they should direct their anger instead. In *The Cancer Journals*, for instance, Lorde poses the question of "what would happen if an army of one-breasted women descended upon Congress and demanded that the use of carcinogenic, fat-stored hormones in beef-feed be outlawed" (14-15). She also uses the image of the one-breasted Dahomey warriors, who cut off one breast to be better archers, to symbolize breast cancer patients, thus transforming the image from a victim who needs to cover up the amputation behind prosthetics, to someone who has claim over her body.

Again, Boyer transforms the hair loss caused by chemotherapy as a tool of protest. The passage begins with the title "communique from an exurban satellite clinic of a cancer pavilion named after a financier." She then writes:

Pull your hair out by the handfuls in socially distressing locations: Sephora, family court, Bank of America, in whatever location where you do your paid work [. . .]. Put your head out the window of the car and let the wind blow the hair off your head. Let your friends harvest locks of your hair to give to other friends to leave in socially distressing locations: to scatter at ports, at national monuments, inside the architecture built to make people feel small and stupid, to throw against harassers on the street. (*Undying* 47)

Similarly, she writes elsewhere: "If I die from this cancer. I tell my friends, cut my corpse into pieces and send my right thigh to Cargill, my left hand to Apple, my ankles to Proctor and Gamble, my forearm to Google" (65), alluding to a Jeans Jacket worn by an AIDS activist that said "If I die of AIDS—forget burial—just drop my body on the steps of the F.D.A" (Boyer, *Undying* 296).

Apart from these straightforward angry protestations, like her poetry collection *Garments Against Women*, unnoticed labor, minimum waged labor, and labor's costs on daily life are deeply embedded in Boyer's narrative. For instance, when she relays the moment she goes to the hair salon to cut her hair, she writes: "As my hair falls into a pile to be swept up later by a poorly paid assistant with a push broom" (36). Labor laws are also touched upon when she writes about her friend, who is paid hourly and can only assist Boyer in her diagnosis process during her lunch break, because only immediate family is allowed leave from work. Here the political does not only reflect the personal in its inability to provide adequate care, but also in its way of

tampering with human connections: "If you are loved outside the enclosure of the family, the law doesn't care how deeply—even with all the unofficialized love in the world enfolding you, if you need to be cared for by others, it must be in stolen slivers of time" (29). The interlink between the materiality of daily life and how a person experiences their illness, again points to the importance of approaching illness through the second more critical wave of Medical Humanities.

Lorde and Boyer also understand that issues around breast cancer can even reach international politics. Lorde for instance writes: "When I speak out against the cynical U.S. intervention in Central America, I am working to save my life in every sense. Government research grants to the National Cancer Institute were cut in 1986 by the exact amount illegally turned over to the contras in Nicaragua. One hundred million dollars" (A Burst, 78). Boyer makes a similar, yet more lucid connection: "The hash marks of the radiologists are the same as those of the drone pilots. The screen life of cancer is the screen life of all mediated global terror and unreality, too" (27). In the documentary Pink Ribbons, Inc., Samantha King attacks the Cancer Foundation for "pinkwashing" ¹⁴ U.S. foreign policy: "Towards the end of the Bush administration the U.S. government began using breast cancer awareness as a tool of diplomacy in the Middle East as a way they thought of winning the hearts and minds of Middle Easterners, who are angry at U.S. involvement, the invasion of Iraq, so on and so forth, and to me this is the most insidious use of breast cancer awareness, but it's also not surprising" (*Pink Ribbons* 1:31). While some of the "positivity" messages have been exported to the Middle East, they still do not reflect a trend. In Egypt, for instance, breast cancer patients have to deal with completely different issues according to a 2019 article in *The Arab Weekly* by Hassan Abdel Zaher. A large number of women in Egypt experience divorce after being diagnosed with breast cancer, because of misogynistic notions of how chemotherapy takes a toll on women's appearance, as they lose

their breasts and hair. 15 Inadequate healthcare and high poverty rates also force women to seek care at a late stage.

While there are some notable writings on illness in the Arab World, the Illness Memoir has still not taken its place as a genre, but there are some exceptions. Living in the Arab world, politics forces itself into the fabric of daily life and sometimes dominates all other aspects.

Egyptian writers like Ni'mat al-Buhairy (*Yawmiyat Imara'a Mushi'a* [Diaries of a Radiating Woman], 2006) and Radwa Ashour (*Athqal min Radwa* [Heavier than Radwa], 2013) inevitably include politics in their illness memoirs, yet while Ashour's inclusion of politics highlights the disruptive nature of illness and how it prevents her from being present in the 2011 revolution, al-Buhairy, in evoking Lorde's image of the one-breasted women protest, again connects the political to the very nature of her disease:

We are all one-breasted puppets. After the session, each will take her breast out, infuse it with her pains and then transform it to a snake, then we will march alone and in groups, a protest of radiating women, towards the house or villa, or mansion of the Official, who has filled his pockets and treasury with immeasurable numbers of foreign funds to fill the city with carcinogenic plants, vegetables and fruits, toxic air, putrid water, and desperate men with the rotten ideas that instigated our misery. (qtd. in Hussein 105-106) ¹⁶

Like Lorde, al-Buhairy considers her one-breasted figure as a sign of strength and turns it into a weapon. The snake evokes the image of Medusa, but it also conjures the image of ancient Egyptian Pharaohs, with cobras on their heads. In a way, Lorde, Boyer, and al-Buhairy create modern myths that involve the scattering of body parts, like in the ancient Egyptian myth of Isis and Osiris, and the morphing of body parts, a common trope in myths. However, these myths do

not idolize or push the experience further into abstraction, rather they offer striking images to intensify the anger.

Chapter 3

A Women's Writing Tradition

One of the significant scenes in the popular TV show *Mad Men* is when Betty Draper, the ex-wife of the show's lead character Don Draper, is first diagnosed with lung cancer and sits silently in the doctor's office, awaiting her new husband to finish his discussion on her own health and treatment options. The scene, set in 1970, depicts an affluent white woman with social privileges, yet still lacking the basic right to be involved in the discussion of her own health. To think that Audre Lorde, a black lesbian woman, wrote *The Cancer Journals* in the late 1970s and had it published in 1980, puts perspective on the importance of her account. Lorde continuously emphasizes the importance of speaking up and writes: "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 or misunderstood" (17).

To go back to the issues that Jurecic had laid out in her book *Illness as Narrative*, it is important to understand the very practical reasons behind women writing the accounts of their illnesses, and why accounts of illness are written beyond the artistic need. One should also consider that women writing about their illnesses to be connected in some ways, yet still take into account their varying and very different circumstances and experiences. How can one link the writings of women without putting on them the dismissive label of "women writers"?¹⁷ Perhaps the term "tradition" is more suitable, as it shows that the categorization of "women" is not merely made for differentiation, but for tracing linkages between writings that are in constant dialogue, and exploring how innovations of form evolve.

As mentioned in the previous chapter, the autobiographies of Lorde and Boyer flow through different genres; they are both lyrical and angry, personal and political, and a hybrid form between the memoir and the essay. While seemingly innovative, this hybridity is actually part of a larger tradition of autobiographies of women. In her introduction to *Women's Autobiography: Essays in Criticism* (1980), Estelle C. Jelinek writes about the different ways men and women have historically written their autobiographies. Jelinek defends women's autobiographies that have been historically undermined for concentrating on personal lives and domestic issues, as well as their tendency to stray from the chronological narrative that has identified autobiographies of men. She writes:

Surveying quite a number of bibliographies from various countries and periods, one is struck by the number of women writing diaries, journals, and notebooks, in contrast to the many more men writing autobiographies proper. From earliest times, these discontinuous forms have been important to women because they are analogous to the fragmented, interrupted, and formless nature of their lives. But they also attest to a continuous female tradition of discontinuity in women's autobiographical writing to the present day. (19)

Jelinek concludes the introduction by stating that "what may appear new is, in fact, for women the culmination of a long tradition" (20). Lorde's and Boyer's autobiographical accounts are then part of this tradition of women's autobiography, but like the autobiographies of men indicated by Jelinek, they tackle larger social and political issues as well.

Janice Morgan, maintains the same claim in her introduction to *Redefining*Autobiography in Twentieth-Century Women's Fiction (1991), and additionally argues that women's writing traditions have taken a different direction than that of men's tradition. As the

men's tradition veered towards the deconstruction of subjectivity, women, having been historically denied to express themselves in writing, were carving out a female identity, exploring the myriad conceptions of the self. Not only that, but Morgan also reflects on how the eighteenth-century conception of the "fixed, identifiable reality of the self" (6) was being questioned, and how it became apparent that autobiography is not mere mimesis, but rather a "negotiation between event and illusion, the actual and the imaginary, where myth, allegory, and lived experience combine in complex interdependent patterns" (6). When T.S. Eliot wrote "Tradition and the Individual Talent" in 1919, he was creating a conception of a tradition informed by country and race. However, now the idea of tradition encompasses even more categories and should not be bound by nationality and race. 18 While a tradition of women's autobiographies can be traced, as analyzed by the feminist critics above, currently another, perhaps minor, tradition is taking shape as well, which is the tradition of women writing on illness. Throughout her book, Boyer is in constant dialogue with other writing on illness, either as a critique or adding to it, comparing with it and pointing to the existence of an emerging tradition.

Re-visiting Virginia Woolf's literary project, one can see how she was carving out a space for these traditions. Deeply aware of the different aspects of human life still underwritten and neglected, she wrote her two famous essays, *A Room of One's Own* and *On Being Ill*. In *A Room of One's Own*, Woolf explores how the life of women beyond romanticization and vilification was largely missing in literature, and the conditions that created such a lacuna. While a women's life writing tradition has existed outside the canon, even far before Woolf, her essay still emphasizes this erasure. In *On Being Ill*, she calls for a type of literature that puts the body at the foreground of expression rather than taking it for granted as "a sheet of plain glass through

which the soul looks straight and clear" (4). While seemingly separate, both of Woolf's visions spring from the same overarching idea. Kimberly Engdahl Coates in "Exposing the Nerves of Language" (2002) connects Woolf's two visions to assert that *On Being Ill* has at its heart a feminist inclination: "If prohibition from sensing or describing carnal passion bars women from achieving men's level of artistic accomplishment, then illness subtends Woolf's feminist project by enabling women to attain equal license with men to inhabit and experience the body" (252). This feminist project proposed by Woolf, then invariably requires its own language and form.

Illness and Linguistic Invention

As one of the innovators of form, Woolf goes beyond the thematic conception of these traditions to further imagine how such traditions can renew language. In A Room of One's Own she proposes working with an "androgynous mind" (97), and in On Being Ill, she imagines a patient-centered language that can describe the lived experience of illness. In "A Lexicon for the Sick Room" (2019), Emily James considers Woolf's On Being Ill to have anticipated the current trend of narrative medicine, which concentrates on the lived experience of the patient. Through On Being Ill and other diary entries by Woolf, James investigates how Woolf was envisioning a lexical world of illness outside the permeating medical jargon. James criticizes scholars' previous tendency to medicalize Woolf's illness and diagnose her condition using the very same terms she had deemed inadequate, and considers how current scholarship is more aligned with what Woolf was trying to achieve: to look at illness through a humanistic lens. Yet, while Woolf highlighted the importance of finding new language, and continuously commended the work by Sir Thomas Browne, the physician who coined such words as "medical," "hallucination," and "electricity" (James 14), Woolf herself proved to have little coinage for illness. Yet James provides an illuminating discovery, which is Woolf's rich sensory evocations through

compounds of pre-existing words like "spider-thin," "specter-pale," "wind-wrinkled," and "nerve-drawn" (18). These words offer a patient-centered vocabulary that can better reflect the world of the ill. Beyond the lexical world and more philosophically, Kimberly Engdahl Coates compares the work of Woolf and Charles Mauron to again argue how they envisioned a phenomenological aesthetic that puts emphasis on the sensory experience of the ill. *On Being Ill*, then, shows how current debates on illness memoirs fall short. While the project proposed in *On Being Ill* is at the outset aesthetic, it still has a utilitarian function. New language aids patients in describing their inner world more fully beyond the reductive language ascribed to them by the biomedical jargon, yet in doing that, a rich vivid sensory world is also created.

How can one trace the reverberations of Woolf's project in Boyer's and Lorde's work, and how far have they offered linguistic innovations to capture illness? To an extent, one can consider their autobiographies an extension of Woolf's imagined possibilities of literature, as they provide embodied accounts of women in illness. Yet, they even go beyond Woolf's initial premise and reflect even more varied states of being that are underrepresented in literature. Lorde for instance, tries to find a way of inhabiting her post-mastectomy body as a black lesbian woman. Boyer considers the material conditions of daily life and how they cannot be separated from narrative. Yet in alignment with Woolf's ideas, they both create their own language and form that speaks of illness as an embodied experience.

Lorde fully understands the importance of language, and the power of words. She writes: "Each of us is here now because in one way or another we share a commitment to language and the power of language, and to the reclaiming of that language which has been made to work against us" (*The Cancer Journals*, 20-21). This is mostly evident in her coming-of-age autobiography *Zami: A New Spelling of my Name* (1982), which she inventively calls a

"biomythography," again showing that the writing of the self actually entails hybrid genres. The subtitle itself is telling as it shows the way she reclaims her identity by deciding on the spelling of her own name. Recounting the incident behind the spelling, she writes:

I did not like the tail of the Y hanging down below the line in Audrey, and would always forget to put it on, which used to disturb my mother greatly. I used to love the evenness of AUDRE LORDE at four years of age, but I remembered to put the Y because it pleased my mother, and because, as she always insisted to me, that was the way it had to be because that was the way it was. No deviation was allowed from her interpretations of correct. (24)

Growing up in a racist, patriarchal society as a black, lesbian woman, Lorde reclaims her identity that has been constantly written by others. Throughout *Zami*, Lorde tries to connect to her African origins, using the names of African goddesses. *Zami*, the new spelling of her name which she chooses as her title, means lesbian in Jamaican Creole. Choosing *Zami* as her name, connects her childhood quest to write her name to her own liking, with her quest as an adult to create an identity of her own.

While not inventing a new language for illness in *The Cancer Journals*, Lorde renews biomedical language to express her internal emotional state. One example is Lorde's journal entry when she describes her emotional state transforming medical terms into evocative metaphors: "I'm not feeling very hopeful these days, about selfhood or anything else. I handle the outward motions of each day while pain fills me like a puspocket and every touch threatens to breach the taut membrane that keeps it from flowing through and poisoning my whole existence" (9). The image of the "membrane," closed and intact, signifies a need to protect

oneself, and "puspocket," porous and open, signifies the fragility of this attempt. Using it at her own terms, the biomedical lexicon is turned from a tool to evade a patient's experience, to transform into palpable and visual metaphor.

Boyer also uses biomedical terms, more specifically, a list of drug names, to create an image of the quantity of drugs, rather than just stating a number. In a Borgesian manner, Boyer constantly invents books that do not exist. She writes for instance:

I have always wanted to write the most beautiful book against beauty. I'd call it Cyclophosphamide, doxorubicin, paclitaxel, docetaxel, carboplatin, steroids, anti-inflammatories, antipsychotic antinausea meds, anti-anxiety antinausea meds, antinausea meds, antidepressants, sedatives, saline flushes, acid reducers, eyedrops, eardrops, numbing creams, alcohol wipes, blood thinners, antihistamines, antibiotics, antifungals, antibacterials, sleep aids, D₃, B₁₂, B₆, joints and oils and edibles, hydrocodone, oxycodone, fentanyl, morphine, eyebrow pencils, face creams. (161)

This title of an imagined book, while strictly uses the opaque language of medicine, makes the quantity of meds required to heal palpable. Reciting them, one can imagine as each box of medicine is stacked atop the other. Boyer also transforms medical language, but instead of turning it into an evocative metaphor, Boyer instead uses repetition to create a melody of the otherwise unpoetic language.

Boyer's play with sentence structures like using run-on sentences and repetition reflects

Saloman's view that "[t]he essayist literally reveals the development of an individual mind in

real time" (50). However, such grammatical transgressions also reveal meaning. One example is the following excerpt:

To become a cancer patient is to become a system-containing object inside another system that only partially allows the recognition of the rest of the systems in which one is a node and also almost wholly obscures the heaviest system of the arrangement of the world as it is, which hangs around, too, in the object that contains a system (by which I mean "me") as part of the problem in the first place, requiring our latent unhealth just as it profits from our active one.

This system we mistake for everything resides in a system-containing object like a tumor inside a system-containing object like a cancer patient who is a system-containing object inside a clinic, all of it also containing these systems of history.

(66)

With the repetition of "system-containing" object, Boyer weaves a large web that connects these different "systems." Instead of writing long statements on the webs that entangle individuals in social systems, she instead uses the poetic form of repetition to evoke an image of a web that a patient is invariably entangled with and can never get out of.

In describing her pain, Boyer also uses medical language in combination with metaphor, and adjectives, to express pain's myriad sensations. She imagines what she calls "body-tourism" for people to "temporarily inhabit the sensorium of a person in pain" (219). She uses the 1 to 10 scale, not to describe severity, but to explore the varied types of possible pain: "the pillowy congested pain," "the inside-out surprise pain of needles puncturing arms," "the zapping electrical apocalypse of dying-nerve-ending pain" (220). However, after all this description, she

again returns to her original worry about inexpressibility and writes "10. the panicking inadequacies of all genres, a new crisis of transmission—." At the beginning of the section, Boyer is critical of Scarry's claim about pain's inexpressibility, yet it seems that her ending statement, again leaves her in the murky ambiguities of questions on illness. After reading Boyer's descriptions, can one really say that pain is expressible? And even if she manages to create such complex metaphors, can a reader still fully understand and grasp the sensations she is describing? Can the words on this page, no matter how evocative, penetrate a reader's body and be felt? And perhaps the most important question to ask is how important it is to make the experience felt in the first place.

In "Empathy and the Critic" (2011), Jurecic recounts an anecdote by Lucy Grealy at a book reading when she answers back a woman--apparently undergoing chemotherapy--who had asked Grealy how she made sure she got everything right. Grealy plainly says that she's a writer and does not recall, but write, defending her status as an author (21-22). What Grealy defends, however, is the persistent idea, that an autobiographical work is somehow lesser in artistic value. Taking Grealy's view, one could say that empathy undermines the artistic creation, and that illness writing should exclude readers who are moved by the experience as fellow patients. Boyer, in a podcast interview with *Commonplace: Conversations with Poets (and Other People)* in 2019, reveals a different perspective. As an experimental poet that has only dealt with small presses, *The Undying* is considered her first work to reach a larger audience. It is only with this book, because of its topic, that she has found it important to reach more readership. When *The New Yorker* published a conventionalized excerpt of the book in 2019 titled "What Cancer takes Away" that had a more coherent narrative than her book, Boyer was glad when oncologists,

nurses, and patients reached out to her. However, trying to reach out to others, still does not detract from the book's artistic endeavor.

These questions invariably lead to the other overarching question, which is why patients are impelled to tell their own stories. As indicated in the introduction, and even throughout the thesis, the reason is not as straightforward as getting more adequate medical treatment or being heard by doctors, although sometimes these motives also occur. Shoshana Akabas, in an article titled "Why Illness Memoirs Are So Important to Chronically Sick People" (2018) asks a poignant question: "As someone who tells stories for a living, I can't help but wonder: why wasn't I able to tell my own story well enough to make doctors listen?" Akabas, who had Lyme disease, spent a long time getting misdiagnosis after misdiagnosis by different doctors, and was oftentimes dismissed as suffering from emotional distress. Reading Sick, a memoir by Porochista Khakpour published in 2018, also about the ordeal of trying to find a diagnosis for Lyme disease, Akabas felt less solitary in her suffering. Akabas knows that no narrative is adequate to capture the reality of the experience of illness, but she still considers the importance of a work like Khakpour's. To Akabas, illness memoirs are a collective endeavor, where each work will complete the other, to create what is like a "database" for illness narratives. Through this collective, and not through one narrative alone, can there be actual, tangible change in the healthcare system.

Underlying the article's advocacy for illness memoirs lies another issue, which is the sexism in healthcare. Men Akabas talked with, generally got diagnosed immediately, and their pain was believed more easily. Tracing works referred to in this thesis, including theoretical work, there is an evident dominance of women's names, especially as one approaches more recent works. The main names in the thesis, include Woolf, Sontag, Lorde, and Boyer, while

others cited, prominent in the field of Medical Humanities, include Jurecic, Carel, and Toombs, but also briefly mentioned are Leslie Jamison, Eula Biss, Lucy Grealy and Porochista Khakpour. While this may be an author's own bias, having all these names as some of the most readily-available examples on writing on illness, can still reflect that writing on illness is not just a medical issue, but also a feminist one. The level of embodiment that an illness narrative requires, gives women claim over their bodies, which have been consistently appropriated and objectified by men.

Conclusion

While innumerable titles are published every day, life writing on illness can still be considered as a continuum, a tradition that is slowly gaining form and will shift and change with the emergence of new cures, illnesses, and healthcare policy, but also with the change of the different platforms of expression. Apart from the traditional mediums indicated in this thesis like different literary forms and film, patients and artists alike are using all different mediums to explore their illnesses from Youtube videos, blogs, photography, to the other online platforms and forums. One interesting example is a blog for online discussion titled *MedHumChat*, which has recently posted a chat discussing Emily Dickinson's poem "Pain has an Element of Blank." One of the questions posed relates to the poem's resonance with readers' experiences; the other question is the following: "What can we take from Dickinson's poem and Eula Biss'[s] essay "The Pain Scale" to improve the care of patients in pain?" (n.p). These choices, of using a poem from the nineteenth century along with a recent essay, and the questions, which revolve around people's experiences and how the healthcare system could be changed, reflect many points in the thesis. Dickinson's poem is used in a context that emphasizes its enduring status, not only for its literary merit, but also for how people relate to it. Of course, the fact that centuries later, it still resonates with readers, also confirms its literary merit. Connecting the poem to a recent essay on pain, again implies that illness creates a shared world that transcends temporal borders.

When Virginia Woolf wrote *On Being Ill*, she was still feeling her way in the dark, trying to form an expression of something that still has no clear form. Now a century later, modes of expression are devised, but questions on how to actually capture this sometimes life-shattering, life-changing, tormenting, horrible, but sometimes transcendental experience still persist. As stated in the third chapter of this thesis, trying to find a language for the lived experience of

illness has at its core a utilitarian function. Yet still, Woolf's concern was largely aesthetic, and as much as her essay can open up numerous discussions, it still views an ill person as one that can stay for endless days in bed, floating along his imagination. Along the spectrum of people with chronic, and autoimmune illnesses, and those recovering from illnesses such as cancer, in addition to people with disabilities--something which I have not delved into at all in this thesis, Woolf's ideas can be considered romantic. Yet perhaps, this can also be regarded as an ideal that should be sought in the fight for adequate care for all.

It is now apparent that function is inherent in illness narratives. In the cases of Lorde and Boyer, both wrote specifically sections on why they were writing on illness. While this might be considered as undermining the "art" of it, both Lorde and Boyer undertake some interesting play with language, and in the case of Lorde, as with all of her other writing, it is poetic, sensual and beautiful. Their experimentation with form, especially in the case of Boyer, is partly impelled by the exact need to find the right expression for what had befell her. G. Thomas Couser's ideas in "Genre Matters" offers an insightful concept which is to regard "genre as function rather than form (or form as function)" (141). This idea relieves genre from its restrictive meaning, and complies to what the thesis argues, which is that the mixture of different genres can help in expressing illness in a richer way. Even Tolstoy, who wrote a fictional work without being ill himself, wrote out of a desperate need to understand the meaning of life through illness and death. Reading *Confession*, it is immediately clear that Tolstoy was undergoing a severe existential crisis. Yet, perhaps in that sense one could then argue that all literature is written out of a certain need, and that with illness writing, the need is just more pronounced and straightforward.

While illness narratives have a clear function, their outcome is not as easily identifiable. At the outset, each narrative tries to come closer to capturing the experience of illness. Yet, just as Sontag has criticized totalizing metaphors for obscuring the meaning of illness, the repetition of some narratives, like the breast cancer positivity story, sometimes undermines the meaning of the illness. Does that mean that the answer lies in writing a story more effectively? While the myriad examples in this thesis have shown why transgressive narratives like Lorde's and Boyer's are more effective, it is perhaps important to consider how the women writing these positive stories are mostly patients writing their stories, who were not formerly writers. Putting much emphasis on narrative, then risks only conveying the stories of patients who are capable to express themselves. As a result, there should be less emphasis on "narrative medicine" in the field of Medical Humanities, and more emphasis on the varying forms and platforms of expression. As the outburst of the illness memoirs were instigated by the AIDS movement, perhaps it should also inspire the current approach to breast cancer to create a movement that combines protest, art, and literature, and one that also inspires patients to collaborate, be angry, and express their illness in the myriad of forms available, and not only through the form of narrative.

Endnotes

¹ The emphasis in this quote, along with all others in the thesis, is the author's own and not mine.

² Contextualization does not have to necessarily mean putting these sensations into a coherent narrative, rather it means contextualizing it within a larger framework, even if this framework is the network of family. An interesting example of contextualizing pain sensations is Eula Biss's "The Pain Scale." Using the ineffectual pain scale metrics, Biss takes each number on the scale, starting from 0 to 10 to reflect on what her pain means. In meandering prose, Biss tries to describe her own chronic pain, while contemplating larger philosophical and political questions, and relays her relationship with her father, a medical doctor, who is not easily affected by other people's pain.

³ This spelling is the author's own and not mine.

⁴ The claim that readers will turn to themselves is somewhat general, as one cannot know what each reader will perceive. However, Smith's claim is one indication. Another example that also cannot be used to make a general statement, but is still revealing, is an informal book club I have once attended, in which this book was discussed. The discussion of the book led to a discussions reflecting on our own lives, and our perception on our own mortality.

⁵ The translation is mine. Original text: "ولم يدهش حين أخبره الطبيب أن المخدر في حالة كتلك ضعيف المفعول لا ينجح عادة في تسكين الألم، فآلام هذا النوع من السرطان أقوى من المخدرات وكل المسكنات التي اختر عها الإنسان" (ص 8).

⁶ This literary trope, which romanticizes village life and depicts the peasant like Gerasim at ease with his life, dates back to the classical Greek novel *Daphnis and Chloe* by Longus. The popularity of this trope is understandable, as it describes village life more of an Eden lost than a real village. Longus's novel itself has been republished during times of war, showing the human need for this type of antidote in times of strife.

⁷ The translation is mine. Original text: والذين ينامون سرعان ما ينزلون/ نحو نهر الحياة كي يسبحوا / أو يغوصوا بنهر "السكون" (ص 401) "السكون" (ص

⁸ Despite this claim, the global Corona pandemic indicates that the idea that we have completely passed the age of infectious disease cannot be used generally or at face value.

⁹ In writing that claim it is still important to note that in the U.S. the mortality rate of black women exceeds white women by 40%.

¹⁰ Boyer cites a study that indicates that "45% of mastectomies in 2013 were performed in hospital-affiliated outpatient surgery centers with no overnight stay" (156).

¹¹ Boyer's proclamations on the state of healthcare hint at why the campaign of Bernie Sanders with its prominent program/slogan "Medicare for All," has gained such momentum. But of course, there are also various other reasons that have popularized this grassroots campaign.

¹² In a section at the end of Daudet's translated *La Doulou* titled "A Note on Syphilis," the book's editor and translator, Julian Barnes, writes an interesting anecdote. A friend of Barnes, who is a specialist in sexually transmitted disease, recounts the story of a group of young people, who travelled to Moldova and

all came back with Syphilis. Barnes compares how easily they got treated to Daudet's account and writes: "If any of them were to read *La Doulou*, they might realize how great their historical luck had been" (87).

- ¹³ While this statement sounds extreme, it is not the general viewpoint of physicians at that time. In addition, Galen's ideas, while faulty, have led many physicians to resort to other healing practices than the knife. In the nineteenth century Halsted emerged with the ideology of "radical" surgery, which has gradually proven not to be always necessary, and that cutting more flesh did not always mean a more propensity to cure.
- ¹⁴ The term 'pinkwashing' was first used by activists against companies profiting from breast cancer awareness. It is now also a term used to describe the manipulation of the LGBTQ cause to promote a certain organization or country as progressive, while covering up other human rights violations.
- ¹⁵ A study by Ghada Ajjar Nassaf et al., in which several interviews were conducted with breast cancer patients indicates that breast cancer is still stigmatized in the Arab world, in the domestic sphere as well as the workplace.
- "نحن جميعاً عرائس بثدي واحد. بعد الجلسة ستخرجه كل واحدة وتنفخ فيه من آلامها :The translation is mine. Original text أو قصر السيد المسئول الذي ملأ جيوبه ثم تحوله لثعبان ثم نجري فرادى وجماعات في مظاهرة من النساء المشعّات في اتجاه بيت أو فيلا أو قصر السيد المسئول الذي ملأ جيوبه وخز ائنه بترف عمو لات أجنبية مرعبة الأرقام ليملأ المدينة بنباتات وخضروات وفاكهة مسرطنة وهواء مسموم وماء فاسد ورجال بائسين بنواتات وخز ائنه بترف عمو لات أجنبية مرعبة الأرقام ليملأ المدينة بنباتات وخضروات وفاكهة مسرطنة وهواء مسموم وماء فاسدة ساهموا في قهرنا."
- ¹⁷ Christine Brooke-Rose writes for instance: "As I have suggested, one *safe* way not to recognize innovative women is to shove them under a label, and one such is 'woman writer'" (67).
- ¹⁸ When looking at the case of Radwa Ashour's *Athqal min Radwa*, it is also apparent that this women's autobiographical tradition is transnational. Ashour also uses a hybrid form of writing that includes the critical essay, the diary form, and the memoir. However, according to Hala Kamal in her article "From Autobiography to Life-Writing: Trajectories and Intersections across the Humanities and Social Sciences" (2020), Ashour's alternation between the personal account and the critical essay adheres to the traditional Arab form of autobiography, and her usage of the writing device of addressing the reader directly with "عزيزي القارئ وعزيزتي القارئ وعزيزتي القارئ وعزيزتي القارئ وعزيزتي المعادة (dear reader: addressing a male and female reader), is taken from the Arab oral tradition. What is then interesting about these traditions is that they are not enclosed, as here Ashour is both part of her specific culture's tradition, as well as from the transnational women's tradition.

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