

# **Transfiguring Self in Diseased Tales: A Reparative Reading of Illness Narratives**

Dissertation submitted to Mahatma Gandhi University, Kottayam in partial recognition of the requirements for the award of the award of postgraduate degree of Master of Arts in English

Language and Literature

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## Certificate

This is to certify the thesis *Transfiguring Self in Diseased Tales: A Reparative Reading of Illness Narratives* by Aparna M.S, Register Number 200011004360 is a record of bona fide work carried out by me in partial fulfilment of the requirement for the award of the post graduate degree of Master of Arts in English Language and Literature.

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## Declaration

I, Aparna M.S, hereby affirm that the thesis titled *Transfiguring Self in Diseased Tales: A Reparative Reading of Illness Narratives*, is a genuine record of work done by me under the guidance of Dr. Mini M Abraham, Post Graduate Department of English Bharata Mata College, Thrikkakara and has not been submitted previously for the award of any degree or diploma.

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## Introduction

### Lived Experiences of Illness

Susan Sontag, an American writer and philosopher states in her *Illness as Metaphor*, “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 pass-port, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (Sontag 3). Sontag here explicitly indicates the most certain classification of people; either ill or healthy. However, she mentions the fact that although people would prefer a life of health and comfort sooner or later they will encounter illness.

Disease or illness’s acquaintance with humanity can trace back to the very origin of human beings. Yet, as Virginia Woolf points out, literature seldom addressed illness unlike other themes of love and war. And this observation is certainly true (Woolf 3). The outbreak of 1918 flu undeniably had a great impact in the emergence of illness in literary space. Till then the front page of newspapers were captured by the bloodshed of war zones (Jurecic, 4). In Woolf’s observation, “English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver and the headache” (Woolf 6). HIV or AIDS outbreak were perceived by the world through stigmatizing frames. They were at certain point of period were distinguished as gay diseases, resulting in strong protests. As an aftermath of these, twentieth century witnessed emerging narratives of illness. The representation of illness through narratives and through other media was becoming an integral part of literature as well.

Illness narratives in literature are personal accounts of illness. It may include journals, autobiographies, memoirs etc, which shares the experiences of illness most probably by individuals who suffer from a particular medical condition or by a close relative. Illness narratives emerged as a space, not just for the representation of a medical condition, rather as

an account of pain, suffering and survival. Diseases or illness, which were only discourses of medical realm found its way to literature through these personal and intimate writings.

Illness narrative includes autobiographical narratives, which are often addressed as autopathographies, memoirs, journal writings, etc. Major themes projected by these narratives are those of fear, dilemma, hope, trauma and death. This thesis is fashioned on autopathographies which are lived experiences of illness by the patient about their vulnerabilities and mostly survivorship upon the strike of a disease. Similar to the generation of personal histories on a particular historical events, every disease or physical illnesses do have multiple individual experiences to share; each distinctive from one another. "Bodily dysfunction may stimulate what I call *autopathography*-autobiographical narrative of illness or disability-by heightening one's awareness of one's mortality, threatening one's sense of identity, and disrupting the apparent plot of one's life. Whatever form it takes, bodily dysfunction tends to heighten consciousness of self and of contingency" (Couser, 5). These narratives provide deeper insight in to one's own life and its purpose in the face of death. Death is the greatest truth of one's life. Upon the realization of being conquered by a malignant disease, the life one had been living over the years could turn upside down. Most of the people start interrogating themselves and reality of their lives. The effect of a malignant disease does not limit to the patient. But rather it affects people around them as well; like family, relatives and friends. Conventionally, the doctors and relatives are the people who have an upper hand in a sick person's life. Seldom interest is shown for the patients' record of their illness. Thus, through such narratives along with the description of a medical condition, its diagnosis and its treatment methods, a patient is given voice to articulate his encounter with the disease and illness develops in to a narrative form.

Similar to the taboos and stigmas that surrounded AIDS and tuberculosis and other terminal diseases, cancer is no exception. Cancer patients are often seen embedded with

shame and guilt. Just like drugs and sex are regarded as the sole reason of having AIDS, patients are often held responsible for their condition. But this analysis is not always accurate. There are people with healthy habits who have cancer. 2020 witnessed a transformation from the title person-of-guilty to that of a “fighter” (Nole, 337).

The centre of study of this paper are two autopathographical accounts both dealing with the medical condition of cancer; Paul Kalanithi’s *When Breath Becomes Air* and Audre Lorde’s *The Cancer Journals*. *When Breath Becomes Air* is an unfinished autobiography of Dr. Paul Kalanithi. It is a breathtaking narrative of Kalanithi’s encounter with cancer. He was diagnosed stage four lung cancer at the age of thirty six. He was a successful neurosurgeon who was invested in queries of life and mortality. Curious about the worthiness of living Paul Kalanithi eventually venture to transform his life in to an exquisitely meaningful one. Paul Kalanithi died on March 9 2015 leaving the book unfinished.

Audre Lorde’s *The Cancer Journals* is a stupendous portrayal of her breast cancer experience. She chronicles her encounter with breast cancer as a black lesbian woman, the period between her biopsy and mastectomy, and her strong disapproval in wearing prosthesis. She criticizes the hypocrisy and double standards of a society that urges women to conform to the body myths of society. Lorde emphasises on the significance of lived experience of illness.

This project makes use of Eve Kosofsky Sedgwick’s concepts “Paranoid Reading and Reparative Reading” from her *Touching Feeling* and Arthur W. Frank’s quest narratives, which he mentions in his *The Wounded Storyteller*. With the help of these concepts this project attempts to trace how individuals when encountered with terminal and malignant cancer acknowledges their pain, suffering, fears and mortality gallantly and how their sharing of lived experience through narratives is an act of resistance resulting in the transfiguration of self.



Morover, the project attempts to answer the question why such constructions of lived experience of illness are significant and what does it offers to its readers? Both Paul Kalanithi and Audre Lorde, in their act of narrative construction offer its readers worthwhile experiences and life lessons. These personal accounts of are shared not as an act of providing awareness to the public, rather both Kalanithi and Lorde in this act takes a deep dive to themselves as well.

The first chapter “Lived Experiences of Illness” will provide a brief overview of the emergence of illness narratives and how it is perceived so far. “Theoretical Approach to Illness Narratives” is the second chapter which frames a theoretical approach with concepts of “Paranoid Reading and Reparative Reading” offered by Eve Kosofsky Sedgwick and “Quest Narratives” by Arthur W. Frank. The third chapter “Worthiness of Living” analyses the reparative traits in *When Breath Becomes Air*, and how through the construction of this narrative and through the acknowledgement of his scared body and self Paul Kalanithi underwent a transformation of self while making death meaningful through living. Fourth chapter “Self Love and Resistance” studies Audre Lorde’s *The Cancer Journals* and examines the reparative practices taken by Audre when she was diagnosed with breast cancer, in her decision of mastectomy and how through exposing the politics behind prosthesis and accepting her one-breast self she undergoes a metamorphosis of self. The final chapter “Terminal Illness and Sense of Self” summarise the findings from this study that reparative reading and writing practices undertaken are beneficial for both the writer and the reader, and through such a construction of narrative and sharing their lived experience the teller evaluates their past, present and self, which results in the transformation of self, which is not a newly emerged one, rather a part which always had been part of them. It answers the question why reading illness narratives and what does it offers for its readers.

## Chapter 2

### Theoretical Approach to Illness Narratives

Eve Kosofsky Sedgwick is a queer theorist, who in her “Paranoid Reading and Reparative Reading”, a chapter from her *Touching Feeling*, discusses about paranoid and reparative reading practices. Paranoid reading reads a text to know what is beneath the text, the really real. It seeks true knowledge. Sedgwick investigates in to paranoid reading and practices, and argues that this “hermeneutics of suspicion” is “synonymous with criticism in itself” (Sedgwick 124). That is criticism had become nothing less than a sceptical reading of the text. Critics are often busy with digging the truth underneath a text and making anticipatory remarks. Thus Sedgwick argues that “...paranoia has... become less a diagnosis than a prescription” (125). Paranoid reading “anticipates” that something bad to happen so that it is not a “surprise” (130).

Eve Kosofsky Sedgwick in her “Paranoid Reading and Reparative Reading” offers an alternative approach to this suspicion in interpreting. She is not objecting to the paranoid reading practice and denying it completely. As she puts it “Paranoia knows some things well and others poorly” (Sedgwick 130). Paranoid criticism revolves around its “faith in exposure” (139). Sedgwick wonders about the purpose of such an exposure, an assumption that any narrative will surprise the reader with some disturbing facts, something contradictory or manipulative or violent.

Sedgwick mentions alternatives for paranoid reading practices. That is, she places “reparative reading practices” parallel to paranoid reading practices (150). She does not disown the paranoid reading practice, rather emphasizes that both exist in a text. She suggests reading a text in opposition to the one that surrounds suspicion. She draws on Milanie Klain’s concept of “depressive position” (128). “Paranoid position” is placed in contrast to depressive position (128). A person who is in paranoid position is recognized drawing from his external

environment delusive impressions. On the contrary, in depressive position he will acknowledge the situation he is in and build upon the parts surrounding him to rebuild himself.

By contrast, the depressive position is an anxiety-mitigating achievement that the infant or adult only sometimes, and often only briefly, succeeds in inhabiting: this is the position from which it is possible in turn to use one's own resources to assemble or "repair" the murderous part-objects into something like a whole- though, I would emphasize, *not necessarily like any preexisting whole*. Once assembled to one's own specifications, the more satisfying object is available both to be identified with and to offer one nourishment and comfort in turn. (128)

As Sedgwick states it is not a restoring of something that existed before, rather it repairs and gives solace in return. Thus, reparative reading practices are about "seeking pleasure" from a surrounding that projects hatred, delusions or negative impressions (137). According to Sedgwick critics should follow reparative reading practices, the impulse which she argues "... wants to assemble and confer plenitude on an object that will then have resources to offer to an inchoate self" (149). Thus reparative reading practices offer openness to text. It scrutinizes the positive side of a text which might probably lack the same.

#### Reparative Reading of Illness narratives

Illness narratives are so far considered as paranoid. They rarely become part of the mainstream literary genres as critics often doom these texts as less appropriate for judgement: "...these critics expect them to fail both as acts of testimony and as works of literature" (Jurecic 11).

Even when such works are written by respected writers such as Harold Brodkey, Anatole Broyard, Maxine Kumin, Audre Lorde, or William Styron,

they may seem to be self-indulgent manipulations of sentiment and goodwill. Other critics emphasize that life writing is a product of ideology and an extension of Enlightenment rationality that places the individual at the center of thought. In this framework, the project of personal writing about illness is doomed before it begins. (10-11)

As Sedgwick argues reparative reading offers resources to an “inchoate self” (Sedgwick 149). Likewise, reparative writing practices can help its writer to understand himself and the situation better, and thus constructing a self by taking care of oneself. Autobiographical illness narratives or memoirs or journals by patients shares their everyday experiences along with the encounter with their medical condition. For these narratives are about illness and patient bodies, they are least expected to project optimistic thought. It was only after the twentieth century that illness narratives emerged as literary products and then came in to the critics’ consideration. Nevertheless, reparative reading and writing practices of illness narratives could engage both the reader and writer in empathetic reception of everyday experiences respectively. “...the reparative reader helps himself again and again” (150). Illness narratives provide form and shape to illness. “...an engaging story engenders an affective and embodied experience that can motivate curiosity and learning” (Jurecic 121). “When Sedgwick makes clear that the experience of cancer is a significant part of her turn to reparative practice, she also indicates that such practices may be particularly valuable for writers and readers of narratives about illness, not just critics” (Jurecic 107).

#### Quest Narratives and Resistance to suffering

Now diseased bodies are so much the centre. The reparative writing of illness experiences are also part of this development and are evidently increasing. Reparative reading and writing practices itself are engaged in exploring the more optimistic side. Thus arise a question - what do these narrations of illness, suffering and pain do? Arthur W. Frank

in his *The Wounded Story Teller* (1997) discussed about three types of narratives: the restitution narrative, the chaos narrative and the quest narrative. He accounts,

Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience. (Frank 115)

Quest narratives acknowledge the illness, pain and suffering. A quest is happening in such narratives and it can differ from narratives to narratives.

Illness narratives are quest narratives where Arthur Frank considers illness as a journey. To describe this journey of illness Frank cites the moral philosopher Campbell's *The Hero with a Thousand Faces* and delineates different stages of it. First stage is "departure", which "in illness stories is the call of symptoms" (117). This stage marks the beginning of an illness, when the patient feels any sort of deviation in her body. The second stage is "initiation" which includes the suffering of all sorts, "physical, emotional and social (118)." The third and final stage is "return" where "the teller returns as one who is no longer ill but remains marked by illness..." (118). Through the explicit description of quest stories Arthur Frank emphasises that "quest stories of illness imply that the teller has been given something by the experience, usually some insight that must be passed on to others" (118). Thus illness stories narrated by a patient herself, which are quest stories, exhibits the experience and the understandings one gained in that journey. The reader of a quest narrative thus encounters along with the patients pain and suffering, these knowledge as well.

Arthur Frank describes this quest as "self-stories" where a transformation of self takes place (128). And this change is not necessarily to a newly constructed self; instead it was the part of the teller always. "The past is reinterpreted in terms of the present and takes on an

enhanced meaning” (129). Frank states, “realizing who they always have been, truly been, each becomes or prepares to become the re-created, moral version of that self” (131).

Although quest stories delivers a hero who efficiently acknowledges his illness and faces his pain and suffering, Frank points out the chance of “romanticizing illness” (135). Not all narratives about illness are quest narratives by a hero who successfully encountered his disease and came back to his life without any scars. Rather the narrator will have scars and markings to remind him or her of their illness and the probability of the narrator to come back to his life should also be taken to consideration. It is not necessary for them to win over their illness. Some might surrender to their illness to death. Thus Arthur Frank takes two other narratives which he mentions in his book as antidotes to this when he says,

The antidote to this pretense of invulnerability is chaos stories, reminding us that some situations cannot be risen above. Most significantly, quest stories risk romanticizing illness. Here the antidote is restitution stories, reminding us that any sane person would rather be healthy, and most of us need the help of others to sustain that health. (135)

Arthur Frank argues that “telling stories” of illness is a mode of “resistance” and “...resistance through the self-story becomes the remaking of the body-self” (170).

In the subsequent chapters, the two texts *When Breath Becomes Air* by Paul Kalanithi and *The Cancer Journals* by Audre Lorde, which are narratives on illness and suffering, will be analysed through the lens of reparative and paranoid reading to find instances of each within the texts. The researcher will investigate how telling self stories becomes a quest and turns out to be an act of resistance resulting in transformation of self.

## Chapter 3

### Worthiness in Living

*When Breath Becomes Air* (2016) is an unfinished autobiography of a young neurosurgeon Paul Kalanithi, who suffered stage four lung cancer and died at the age of thirty-seven. A terminal illness like cancer transformed Paul's life topsy turvy. The autobiography begins with a prologue following two main chapters and concludes with an epilogue by Lucy Kalanithi, Paul's wife. The prologue delivers the diagnosis stage of his cancer. The first chapter deals with his life before illness and the second chapter with the confirmation and treatment of his cancer. As Lucy Kalanithi details in the epilogue, Paul did not complete writing this book. He left the world before its finalization. He was obvious about it. Moreover, what makes Paul different is he was vigorously in love with literature as well. He was a post graduate in literature. Although it is an autobiography, for the most part it narrates Paul's sufferings, his pain, his and his family's confrontation of the illness, and his curious thoughts on life and death. Thus, this autobiographical account of Paul Kalanithi could be taken as an illness narrative where the doctor-becomes-patient experience is explicitly chronicled.

"Paranoid" reading of this book certainly provides the reader with doubts, pain, fear, sufferings, etc, which the text, as an illness narrative patently offers (Sedgwick 128). However, on its brighter side, "reparative reading" of the text could visibly analyse the acknowledgment of illness by Paul, confrontation of his pain and suffering, and openness to his reality (150). What makes this book a gripping narrative is "...the obvious fact that its author was such a brilliant polymath. And part comes from the way he conveys what happened to him — passionately working and striving, deferring gratification, waiting to live, learning to die — so well. None of it is maudlin. Nothing is exaggerated" ("Review: In 'When Breath Becomes Air,' Dr. Paul Kalanithi Confronts an Early Death"). In order to trace

the reparative attributes of the text, Paul's narrative is analysed as a quest narrative that undertakes a journey of his illness beginning from diagnosis to sufferings, at emotional, physical and social levels, to the stage of recognition of his reality. Furthermore, this chapter examines the transformation or the making of a self and identity eventually occurring in the process of narrative construction and how it becomes an act of resistance.

In a paranoid frame of reference Paul's illness narrative might only project the anxieties of his cancer. For paranoid reading is "anticipates" dangers, Paul's experience will only project fear of death, lose of dreams and failure in treatments (130). It might also conclude that Paul's acknowledgment of his illness arouse from his privilege as a doctor. In order to track down the reparative features of this work and the reparative practices embraced by Paul Kalanithi, glancing at his past is essential.

Paul's life throughout was engaged in a quest to discover "What makes human life meaningful" (Kalanithi 30)? His career begins with this question. He was occupied with these enquiries of life, its meaning, on human relationships, and the human mind. He gained his degrees in English literature and human biology. As per his assumptions, literature voiced "...the best account of life of the mind..." (31). And this immense fascination for literature can be observed when celebrated writers and their words underline the core of his autobiography. As a young man he empathised with people and their circumstances. Beginning with his father, who was also a doctor, Paul admits that at that time period of his life, he came to the conclusion upon witnessing his father's life that "if that was the price of medicine, it was simply too high" (21). His father came home late at nights and he compromised the experience of fatherhood although he was a dedicated doctor. Paul's visit to people suffering from severe brain injury as part of his academics made him wonder, how parents possibly could abandon their children.



Paul found later in his academic life that English Department is the field where he could not fit in. The answers he was searching for was not in literature, for literary studies always went, he observes, “overly political and averse science” (40). What he desired for was a point where “biology, morality, literature, and philosophy intersect” (41). His journey as a neurosurgeon began at that point. He figured out the possibilities medicine could offer in his quest of exploring the meaning of human life. He realized embracing medicine would grant him a plausibility “...to find answers that are not in books, to find different sort of sublime, to forge relationships with the suffering, and to keep following the question of what makes human life meaningful, even in the face of death and decay” (42). Joining a degree in “history and philosophy of science and medicine” Paul came to realize that he wanted “direct experience of life and death” and it could at best be accomplished through the practice of medicine (43).

Paul Kalanithi’s life as a doctor enthusiastically following his direct experience with human life and death began at Yale school of medicine. He intended to explore the meaning of human life; rather he got indulged in his life as a neurosurgeon. He saw illness, death of people, patients grappling with pain, and their suffering. He empathised with them and respected their identity as an individual. The humanist side of a doctor could be evidently observed in Paul. He, in the first chapter of the book “In Perfect Health I Begin” delineates the doctor side of illness narrative. The humanist aspect in Paul spares the living patient or a dead body their space in the narrative. His observations are vivid and realistic. He states,

In anatomy lab, we objectified the dead, literally reducing them to organs, tissues, nerves, muscles. ...Doctors invade the body in every way imaginable. They see people at their most vulnerable, their most scared, their most private. They escort them into the world, and then back out. Seeing the body as matter and mechanism is the flip side to easing the most profound human suffering.

By the same token, the most profound human suffering becomes a mere pedagogical tool. (49)

As a doctor he observes how a patient becomes mere object in a hospital bed. The dead bodies turn into their specimens. However, the doctor-patient relationship is not concluded to that of an object and an observer. Moreover, he emphasizes on how the concept of “human relationality,” a term he used in the phase of under graduation, which was “the relational aspect of humans”, provides a firm base for understanding the meaning of human life (39). Entering medical school his apprehension was that, this “human relationality realized in the doctor-patient relationship” (51). In his search of life and death experience he came to the conclusion that death is a constant. Any organism in the whole world, whatever their life’s happenings, ultimately will die. Death is the ultimate truth of all living beings. He saw life and death phenomenon right in front of his eyes. He witnessed the birth of twin babies and due to unfortunate circumstances their death as well. Paul is reminded of lines from Samuel Beckett’s *Waiting for Godot*, “One day we were born, one day we shall die, the same second.... Birth astride of a grave, the light gleams an instant, then it’s night once more” (65). Birth and death were vague concepts for him. Later on he thinks “Beckett’s Pozzo is right. May be life is merely an “instant,” too brief to consider” (66).

Paul chose neurosurgery as his speciality. And this decision also awakened from his thoughts of life and its meaning. He remarks that neurosurgeons, unlike other doctors, do hold an indispensable role in the identity of patients, since brain surgery is “a manipulation of the substance of our selves...” and it “...has the impact of any major life event” (71). Furthermore, in the course of these crucial moments “the question is not simply whether to live or die but what kind of life is worth living” (71). Every single patient when assigned for a surgery with a neurosurgical problem will have to answer these questions, what makes their life keep going? What does make it meaningful? Paul’s views on life, its meaning, and death

found its form during his residential period. Each patient he encountered formed his understanding of these concepts as he witnessed their pain and sufferings. His life as a neurosurgeon accustomed him to the worst of sufferings. Certain encounters, when he never drowned to those details of patients, made him fear that he might be turning in to "...Tolstoy's stereotype of a doctor, preoccupied with empty formalism, focused on the rote treatment of disease- and utterly missing the larger human significance" (85). He feared he might lose the gravity of relationship between a doctor and a patient. He perceived his patient as "a person, instead of a problem to be solved" (90). Before operating in to a patient's brain, before placing his authority as a doctor on an ill body, Paul respected the individual in front of him, their values, "what makes his life worth living" (98)? Nancy K. Miller, Professor of English and Comparative literature states "Individuals become patients in a specific clinical setting with its cadre of physicians trained according to a specific medical protocol, and beliefs about rights to life and death. Treatment is political" ( Nole 337). Paul Kalanithi differed from this stand point, since he searched for meaning in lives before him.

Above analysed phase of Paul Kalanithi's life showcases the stage before his diagnosis. Prior to his illness he wanted to explore the meaning of life, and inquired "if the unexamined life was not worth living, was the un-lived life worth examining" (31)? Arthur Frank observes, in *The Wounded Storyteller* that the "present circumstances become occasions for the recollection of certain past events" (Frank 120). The present circumstance in Paul's life is his diagnosis of cancer. Being a doctor Paul analysed as many scans of his patients, he described their illness to them, as a resident his primary concern "was not saving lives...but guiding a patient or family to an understanding of death and illness" (Kalanithi 86). Contemplating on his own CT scan, now Paul's role reversed to that of a patient.

Paul experienced deviations in his otherwise normal body, however. He and his family, like any other family, did not want to be informed of cancer invading his body. This

is the “departure stage” of journey of illness undertaken by quest stories of illness narratives, which stands for the “symptoms: the lump, dizziness, cough, or other sign that the body is not as it should be” (Frank 117). The refusal to acknowledge illness is apparently visible when Paul ignores his symptoms. During the journey of illness the “hero” refuses these symptoms, because, Arthur Frank states, “the hero, who has not yet become a hero, knows how much suffering will be involved” (117). And this is a common feature of a “quest story” (117). Paul experienced sudden weight loss and back pain. As a doctor he is certain about his condition. Treating his patients Paul observed that “Any major illness transforms a patient’s – really, an entire family’s – life” (Kalanithi 90). His illness transformed his identity from a doctor to that of a patient. Cancer as a terminal illness “gets the best of the humans. It makes them painfully re-negotiate everything that life has been, bringing out a catharsis at the end” (“The (real) art of living”). Paul wondered why he was confident and reliable as a doctor, and how feeble and puny he is as a patient. He realizes how it is to be a patient. As a doctor he was with his patients in their pain and sufferings, he prescribed medicines, and assured them life. But he never knew how fragile they were while experiencing an illness. Frequent invasion of past interrupting their present with augmented memories, a doctor could never be part of that reality.

Human beings are engaged in a remarkable process of planning their future. The shock accounted in illness narratives partly emerges from their disappointment. When a terminal disease strikes unexpectedly life leaves people with a short-lived future. Paul and Lucy Kalanithi envisaged their future, including their parenthood. Both of them were at the peak of their careers. Paul was in his final year of residency.

At age thirty-six, I had reached the mountaintop; I could see the Promised Land, from Gilead to Jericho to the Mediterranean Sea. I could see a nice catamaran on that sea that Lucy, our hypothetical children, and I would take

out on weekends. I could see the tension in my back unwinding as my work schedule eased and life became more manageable. I could see myself finally becoming the husband I'd promised to be. (Kalanithi 7)

With the recognition of his cancer everything both Paul and Lucy dreamt for their future evaporated in to thin air. Illness narratives are not bound to patient alone. Moreover, family of the patient plays a significant role. When Paul identifies his patient self as unreliable and meek, he seeks comfort in Lucy and his family. Initially Paul chooses to suffer alone resulting Lucy to find herself isolated. Lucy makes him realize that they are together in this journey. This emphasises Frank's observation that "Most significantly, quest stories risk romanticizing illness. Here the antidote is restitution stories, reminding us that any sane person would rather be healthy, and most of us need the help of others to sustain that health" (Frank 135). Paul's narrative does not romanticize illness by portraying it as a single venture to recovery by winning over it. However, it remarks the significance of families and others around the patient who offers comfort in the process of healing.

Comprehending the situations through which Paul traversed and the circumstance under which he constructed his self narrative is significant to understand the "reparative" features of *When Breath Becomes Air* (Sedgwick 137). Sufferings afflicted by illness are not limited to physical; rather it is extended to emotional and social. As cancer ascends on to him the pain inflicted on Paul's physical self is beyond toleration. He states,

...my body was rippling with pain. Over the past few months, I'd had back spasms of varying ferocity, from simple ignorable pain, to pain that made me forsake speech to grind my teeth, to pain so severe I curled up on the floor, screaming. This pain was toward the more severe end of the spectrum. I lay down on a hard bench in the waiting area, feeling my back muscles contort, breathing to control the pain—. (Kalanithi 11)

To his astonishment, Paul recognizes now that this is what people with back pain suffer from. The vehement reader in Paul used to get separated from the reality around him while drowning in his book. Now as he observes, it is his miserable body isolating him from his life around, and his "...identity as a physician ...no longer mattered" (121).

Paul consistently searched for direct experience with life and death. Abruptly, death became a steady visitor in Paul's life. He was curious about what makes life worthy to live. In all moments of a surgery, he respected his patient's identity and their values. He closely analysed what is the meaning of human life. After the conformation of his state of illness, Paul was exhausted. He found it hard to identify with himself. While he was living he was after death. Now he is in the verge of death his chaotic self is anxious about what makes his own life worthy of living. "Severe illness wasn't life-altering, it was life-shattering," Paul exclaims (120).

In the course of his residential period, Paul often came across his patient and their family's high-hope statements. They were determined to face their illness head on. He saw his father in their place and is unsure of how to respond to it. "The fact of death is unsettling. Yet there is no other way to live," realizes Paul (132). Him, like any other patient wanted statistical data detailing the probability of life. He desperately asked his doctor for the exact number of days he could live. He was uncertain about his future.

Paul chose neurosurgery over literature in his quest of life and death. In the phase of death he began to search for answers back in literature. He returned to literature in an attempt to regain his former self. He began to give two identities to death: one that of a doctor and the other as a patient. As a doctor he is aware not to declare his war on his disease and aiming victory over it. Gradually Paul and Lucy came to the apprehension that life is not "about avoiding suffering" (143). Paul asserts, "After so many years of living with death, I'd come to understand that the easiest death wasn't necessarily the best" (143). "...We decided to have

a child. We would carry on living, instead of dying” (144). Thus Paul Kalanithi neither contemplates on winning against his illness, nor does he intend to avoid suffering. Death ahead, although Paul experiences meekness, he decides to transform his life worth before dying. It is this transformation Paul undertake and his decision to lead a meaningful life that visibly remarks the reparative aspects of his narrative.

Throughout his journey, Paul saw visible reduction as well as worsening of his tumour. However, with his ill body he goes back to his profession as a neurosurgeon to complete his last year of residency. He and Lucy decided to have a child through IVF, as a first step of realizing their dreams. Paul devoted the rest of his life in regaining his lost self and identity. By acknowledging his illness and the fact that someday he will die, Paul sought solace in literature. He began reading

Solzhenitsyn’s *Cancer Ward*, B. S. Johnson’s *The Unfortunates*, Tolstoy’s *Ivan Ilyich*, Nagel’s *Mind and Cosmos*, Woolf, Kafka, Montaigne, Frost, Greville, memoirs of cancer patients—anything by anyone who had ever written about mortality. I was searching for a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again. The privilege of direct experience had led me away from literary and academic work, yet now I felt that to understand my own direct experiences, I would have to translate them back into language. (148-149)

Paul emphasises that literature brought him back to his track. Samuel Becket’s words “I can’t go on. I’ll go on” enchanted in his ears (qtd. in 149). It was not an attempt in constructing a newer self; instead he was recreating the version which had always been part of him. Paul was learning to live when he finally reached face to face with death. In the face of death he was finally discovering the vitals of his life, those worthy affairs which would give meaning to his life. Earlier Paul desired to experience death. Cancer made him ruminant over that

thought and reach a conclusion that “Death may be a one-time event, but living with terminal illness is a process” and “Grand illness are supposed to be life-clarifying” (161).

Paul, amidst his illness managed to complete his graduation. On the day of his graduation he felt sudden deterioration in his health. That day, which he already knew would be coming, was there. His “diarrhea rapidly worsening,” his “kidneys began to fail,” following which he got in to an ICU (188). He could feel the pain at different levels. Later, on July 4 Lucy gave birth to their hope “Elizabeth Acadia – Cady” (195). Cady illuminated Paul and Lucy’s days ahead. Paul desired more time with Cady, so that he leaves some amount of memories for her with her father. Besides, he wanted to adore her with that fatherhood that was missing in his reminiscences of childhood. Nevertheless, he cherished the time he spend with her. He invested the remaining moments in human relationships. In his final note to Cady Paul writes,

When you come to one of the many moments in life where you must give an account of yourself ... do not, I pray, discount that you filled a dying man’s days with a sated joy, a joy unknown to me in all my prior years, a joy that does not hunger for more and more but rests, satisfied. In this time, right now, that is an enormous thing. (199)

In Paul’s last moments, he held Cady in his arms. In his deathbed, when medicines barely supported his ill body, he prepped himself to pronounce adieu. Suffering following any terminal illness is not restricted to patients, but their family is part of it as well. Although their son was wrestling with his cancer his family stood firmly as Paul and Lucy’s support system. As discussed above, Paul saw his father in the place of his patent’s family who affirmed they will beat the disease. Lucy was always beside him embracing his diseased self and his thoughts. She knew that Paul would rather lead a meaning full life than lying in his



deathbed. She proclaimed, “If he doesn’t have a chance of meaningful time, he wants to take the mask off and hold Cady” (210). Paul Kalanithi died on March 5 2015.

Paul inscribed *When Breath Becomes Air* during his final months amidst the rapid decline of his health. Writing the book was a reparative practice Paul initiated. He was strictly focused on completing this book, although it was left unfinished. Paul refused to accept his illness, he suffered emotionally and physically, the pain inflicted by cancer was unbearable. In his narrative Paul neither exaggerates nor does he conceals anything. As Lucy Kalanithi explicitly phrases in the epilogue, on narrating his story Paul,

...wanted to help people understand death and face their mortality. [The reader] can get into these shoes, walk a bit, and say, ‘So that’s what it looks like from here ... sooner or later I’ll be back here in my shoes.’ That’s what I’m aiming for... Not the sensationalism of dying, and not exhortations to gather rosebuds, but: Here’s what lies up ahead on the road. (215)

The circumstance in which Paul wrote the book is dazing. Terminal cancer brought a sense of purpose in Paul which made him persistent on writing this book. “When his figure tips developed painful fissures because of his chemotherapy, we found seamless, silver-lined gloves that allowed use of a trackpad and keyboard” (214). He spent his life probing the worthiness and meaning of life and *When Breath Becomes Air* manifest the same. Despite being restrained by the pain imposed by his fragile body, and while getting his chemotherapy treatment, Paul was determined to continue his writing diligently. “His ‘dual citizenship’ as a doctor and as a seriously ill patient had taught him that respectful communication is the bedrock of all medicine” (“Paul Kalanithi, writer and neurosurgeon, dies at 37”).

Returning to neurosurgery amidst his deteriorating health, decision to have Cady, reading literature to find meaning in death, and dedicating his remaining months for the creation of his self-story with the full acknowledgment of his painful body and self are the

reparative practices Paul exercised. The first hand experience of death Paul's doctor-self desired for and the one his patient-self had, Paul wanted his readers to "face death with integrity," through the construction of this narrative (216). The path he traversed gallantly, Paul never avoided the thorns in his path. In the construction of this narrative he showcased his vulnerable self. And in this construction of a self narrative a transformation of self could be observed, not necessarily an alternative or brand new one, rather a part of Paul which was always within him or he was. Through writing he accomplished the dream he had as a younger self and this work indeed became an epitome of his love for literature. "Paul faced each stage of his illness with grace – not with bravado or a misguided faith that he could overcome or beat cancer but with an authenticity that allowed him to grieve the loss of the future he had planned and forge a new one" (219).

## Chapter 4

### Self Love and Resistance

Cancer has become a disease the world has deep acquaintance and delivering uneasiness with when diagnosed. And cancer is that uninvited guest who “doesn't knock before it enters” (Sontag 5). *The Cancer Journals* (1980) by Audre Lorde encapsulates journal entries and extended essays on Lorde's breast cancer experience. It accounts a “Black Lesbian Feminist experience” of breast cancer (Lorde 24). Audre Lorde is an American writer, poet who through her poems and writings widely emphasised on issues affiliated with class, gender, and race. She was part of the LGBTQ rights movements. Fearless and vivid articulations in her writing offer voices to those in silence. However, when Lorde places her post mastectomy experience before her readers she does not embellish it by avoiding her pain, suffering, fear and dilemmas. She chose to exhibit her vulnerabilities, as it is encountered by any other cancer patients. What makes her narrative empowering is the acknowledgement of her scared body and self, and her absence of a breast which is supposed to define a woman in society. She converts silence to strong voice to provide strength for those women to acknowledge their situation. “She is empathetic, curious, critical, intuitive. She is as open about her weaknesses as she is about her strengths” (“The Legacy of Audre Lorde”). Audre Lorde's account of her illness, acknowledges the fact that death will certainly find us even if we stay silent or stay voiced. Thus, by constructing such a narrative she decides to open up her fears, vulnerabilities, pain and giving them voice.

Audre Lorde's illness narrative can be analysed by looking at it from three phases: firstly- her pain, sufferings, fears, concept of death and silence; secondly- her acknowledgement of her circumstances and turning them in to her voice; thirdly- transformation of self and construction of a new self through narrative construction. Through

this process the “reparative” (Sedgwick 137) traits of the narrative could also be explored along with how this narration of her self-story becomes an action of resistance (Frank 170).

Although her first biopsy was not positive, Lorde was bombarded in her head with questions of death. She was indeed expecting her death call. Her second biopsy was, however, positive for malignant breast cancer. Yet, the fear, pain and death she expected and almost accepted as her reality during her first biopsy was not something she experienced during her diagnosis of cancer. She was terrified with the very thought of dealing with all these. Since her cancer was malignant mastectomy was the best choice. However, the ultimate decision has to be made by Lorde herself. The thorny path to reach that decision was indeed tormenting for her. In a world where woman is defined by her breast it is not at all surprising. Moreover, she underwent a sense of being alone in that path. She is not familiar with any shared lived experiences of breast cancer patients who had been through mastectomy; not an account at least she could identify with as a Black Feminist Lesbian. She writes, “I have cancer. I'm a black lesbian feminist poet, how am I going to do this now? Where are the models for what I'm supposed to be in this situation? But there were none. This is it, Audre. You're on your own.” (28-29). The significance of shared experiences of illness is highlighted here. Post mastectomy Lorde with Li'l Sister, who is her brother-in-laws younger sister, conversed with both of their experiences of mastectomy and respective standpoints on prosthesis. It was indeed a reparative practice done by Lorde when she looked out for comfort in shared accounts of illness. Her narrative takes a cultural turn when she tells about the

...feast of Kwanza, the African American festival of harvest which begins the day after Christmas and lasts for seven days. There are seven principles of Kwanza, one for each day. The first principle is Umoja, which means unity, the decision to strive for and maintain unity in self and community. The

principle for yesterday, the second day, was Kujichagulia—self-determination—the decision to define ourselves, name ourselves, and speak for ourselves, instead of being defined and spoken for by others. Today is the third day of Kwanza, and the principle for today is Ujima—collective work and responsibility—the decision to build and maintain ourselves and our communities together and to recognize and solve our problems together. (22)

Lorde here takes inspiration from her culture for a deep self analysis and evaluation. Kwanza festival reminds her to preserve the self and encourage for “seeking pleasure” amidst her internal chaos (Sedgwick 137). It also persuades her to “assemble” the pieces inside her to “have resources to offer to an inchoate self” (149).

Nevertheless, Lorde decided to ransom her breast for her life. She contemplated on the many possibilities and alternatives other than mastectomy and finally came to the conclusion that to regain the self and her beloved life mastectomy is the best choice. She emphasises, “...I would have paid more than even my beloved breast out of my body to preserve that self that was not merely physically defined, and count it well spent” (32). Lorde’s intimacy with her breast illuminates the idea that how much it defines a woman. Breast becomes an unavoidable fragment of a woman’s body. Audre Lorde, thus, on sharing her mastectomy experience deals with the notion of personal becomes political (“Audre Lorde Broke the Silence”). And in doing so she raises the question *does breast define a woman?* Most of the women are trapped in the silence this question raises. Lorde was bothered about the absence of her breast, for it held emotional significance for her. She pondered in thoughts of how she could have pleasure in its absence? And, will her partner perceive her as interesting as when she had her breast? The sentimentality attested to her breast is evident when she says “The pain of separation from my breast was at least as sharp as the pain of separating from my mother” (Lorde 25). The pain and sense of lose inflicted on

her is not limited to physical absence of her breast. Rather, it is followed by the psychological, emotional and social sufferings induced consequently. She felt emotionally numb after her mastectomy unable to acknowledge her loss. She states,

...it was as if I had been emotionally anesthetized also...The muscles in my back and right shoulder began to screech as if they'd been pulled apart and now were coming back to life slowly and against their will. My chest wall was beginning to ache and bum and stab by turns. My breast which was no longer there would hurt as if it were being squeezed in a vise. (37)

As the effect of anaesthesia faded, the physical pain occupied her body was overwhelming, much greater than she expected it to be. This pain reminded her of her loss every fraction of a second.

After a mastectomy it is common for women to have prosthesis. And most women choose prosthesis for they do not want any aspect of their body missing. Society often urges women to do prosthesis to confirm to the typical standards of women placed by it. As Lorde shares her experience, a fifty-six year old lady, who had a mastectomy and wearing prosthesis, approached her. Her point was, a mastectomy cannot alter their destiny and they can maintain a body exactly like before and “nobody’ll ever know the difference” (42). Nevertheless, for Lorde the argument was different. She exclaims, “...I knew sure as hell I’d know the difference” (42). She will definitely sense the difference in a prosthesis and her beloved breast. Prosthesis is unable to fill the space and she was certain about not to alter her scared identity and self. Another account of this urging demand for prosthesis was from a nurse, who announced it was “bad for the morale of the office” for Lorde did not wear a prosthesis (52). These accounts of experience prior to and after her mastectomy embody the pain and suffering Audre Lorde encountered on various levels of her life.

Family of the one with illness do maintain a deep role in narratives of illness, since they were an integral part of their illness experience as well. In Audre Lorde's narrative she delineates about "woman love", which comforted her in her state of despair (29). And this family she mentions here is not limited to her blood relatives. Moreover, they are her friends who became her family and provided her with enormous love and care in days between biopsy and mastectomy. Lorde recalls "To this day, sometimes I feel like a corporate effort, the love and care and concern of so many women having been invested in me with such open-heartedness. My fears were the fears of us all" (30). This love gave her strength to not lose herself in the face of pain, loss and despair.

Since *The Cancer Journals* is an illness narrative it is embodiment of pain, despair, loss, fury, and sufferings. "Paranoid" writing of the text will enlarge the already existing dangers and fears of illness in the narrative. Thus, in order to understand the benefits it offers for its readers, an inquiry in to its reparative traits is mandatory as Audre Lorde herself present with reparative writing strategy. Audre Lorde, who is an established writer who raised her voice for the voiceless through her literary creations, when stroked with a malignant cancer, again converts her silence imposed by her loss, fear and sufferings in to "language and action" (18). She, on spitting facts about her emotional state of detachment from her breast does not intend to project it as loss. She decides to come in terms with her mastectomy and her possible reality. The "physical pain" she endured, as Lorde argues gave her strength "for it kept that conscious part of me away from the full flavour of my fear and loss" (38-39).

The "The American Cancer Society's Reach For Recovery Program" volunteers in hospitals were to help those patients to recover their mental state after dealing with a malignant cancer. After mastectomy every women is provided with recovery speeches by these volunteers. As Lorde observes, they are indifferent to the individual vision and analysis

of each patients. Women who amputated their breast are left with no other choice but to jump in for prosthesis. Lorde, by vocalizing the stereotypical standards inflicted by consumer society on women's body, articulates the body politics that plays behind the embellished curtains of prosthesis. After her mastectomy she refused to wear prosthesis, for a prosthesis does not have the capacity to replace her loss. And the loss she emphasises here is not the "appearance" of a swelling on the right side of her chest, instead it was "the feeling and the fact" (65). In doing so, Audre Lorde is open to her vulnerabilities and the scarred body becomes part of her new self. However, similar to the nurse who told her not using prosthesis is a threat to their morale, the whole society is blinded by the need to picturize women in their stereotypical framework. Like the nurse the society wants women to look 'normal' not because these women desire for it, but to satisfy the societal needs. In Lorde's argument she state that the consumerist society plays a significant role on imposing appearances on women (64). The corporate companies that develop prosthesis and the plastic surgery industry are vigorously instigating women who amputated their breast to return to their so-called natural look. For example, Lorde quotes an article appeared in

Early Breast Cancer, Detection and Treatment" which suggests " Remember that what we are doing in the reconstruction of the female breast is by no means a cosmetic triumph. What we are aiming for is to allow women to look decent in clothes, (*italics mine*). . . . The aim is for the patient to look normal and natural when she has clothes on her body. (qtd. in Lorde 69)

Moreover, as Lorde reflects, the advertisements and media have coded "Women ...to view our bodies only in terms of how they look and feel others, rather than how they feel to our selves, and how we wish to use them" (64). This programmed behaviour is evident in the fifty-six year old lady who visits Lorde in hospital. She was blinded by the false hope resulted from such advertisements. They yearn for their past and want that conformation from



the society when they cling on to the idea no one will know the difference (42). However, as Lorde states she will definitely know the difference. These intervention of media in to the intimate self of women and snatches their own chance to evaluate themselves. Besides, Lorde observes how women, after their mastectomy, are kicked out of their jobs for not wearing prosthesis. She questions the hypocrisy of prosthesis for mastectomy. Unlike prosthetic limbs and dentures, prosthetic for breasts are not complementing any functions as a fake breast (63). It merely gives greater emphasis on the idea of looking good. Audre Lorde points out the gender biases in society when they victimize the women after their mastectomy. They are forced to feel guilty for their illness just like “the rape victim is accused of enticing the rapist” (65).

Audre Lorde critiques on society for not concentrating on further research for the betterment of breast cancer treatment and its early identification, and, rather giving unwanted attention for the appearance of female body and thereby objectifying it. She also illuminates the hypocrisy of society when they consider Moishe Dayan, the Prime Minister of Israel, with his vacant eye sockets gallant and woman with her empty chest as guilty.

What fashions *The Cancer Journals* a gripping narrative is that Audre Lorde articulates about her malignant illness parallel to the malignancy of racism as well. Lorde looked out for role models around her, and for books and images before her mastectomy for she was curious how bad it could be. As a result she “came across pictures of women with one breast and mastectomy scars” and she remembers she found it unbearable (77). However, she learned through her insecurities, fear, and scared body to take a deep dive into herself and thereby acknowledging her new self. Her denial of prosthesis is not essentially condemning those who prefer prosthesis. Besides, the complication is when it becomes a necessity not a choice (63). And, these programmes for the awareness of women on prosthesis, denies them

the opportunity to choose. Lorde argues “She is left no space to come to terms with her altered life, not to transform it into another level of dynamic existence” (63).

What does Lorde implies on writing her experience with illness? Lorde wrote a “reparative” account of her illness where she seeks pleasure in her scared body and self (Sedgwick 137). She, through this “quest narrative” faces her illness with dignity (Frank 170). Moreover, her narrative is a form of resistance against stereotyping of women’s body and the false hope evoked in them. This “journey of illness” results in a transformation of self (117). She recognizes that she is also a “warrior” (Lorde 21). In this process to evaluation and recognition Lorde does not conceals her true self. She conducts a profound analysis of herself and identifies with it. The malignant breast cancer gave her courage to deal with her probability of death, which later imparted in her with the realization that in the face of death what matters is yourself. She was more concerned about her future as a writer and her chances of being alive. Being alive was the only matter of fact when you know tomorrow is a question mark. Lorde states in her introduction to her work that she does not desire for the powerlessness coming from the silence inflicted by fear, pain and sufferings. Most post-mastectomy women descend into such silences out of their fear. Lorde does not wish for such collapse and instead she constructs a self, which is not necessarily a detached one. Rather, a part of Lorde which was always present in herself.

Through such a construction illness narrative, Lorde attempts to fill that space which she found vacant when she searched for a role model of Black Feminist Lesbian experience of breast cancer. Throughout her journey her work gave her motive for being alive within (13). Lorde explicitly states,

I am writing this now in a new year, recalling, trying to piece together that chunk of my recent past, so that I, or anyone else in need or desire, can dip into it at will if necessary to find the ingredients with which to build a wider construct. That is an important function of

the telling of experience. I am also writing to sort out for myself who I was and was becoming throughout that time, setting down my artifacts, not only for later scrutiny, but also to be free of them, I do not wish to be free from their effect, which I will carry and use internalized in one way or another, but free from having to carry them around in a reserve part of my brain. (53)

## Chapter 5

### Terminal Illness and Sense of Self

Lived experience of illness were shared and furnished itself as an established literary genre only after the twentieth century. Nevertheless, it was never perceived as worthy of examining or apt for critical reading. Illness narratives could be observed in numerous forms. There are doctor's accounts, patients' and their family's as well. Events narrated by doctors and families are often detached from a patients' narrative. These articulations are heterogeneous in nature. The partition history of India exhibits multiple accounts for it differs from individual to individual and places to places. Likewise, an encounter with same kind of disease not necessarily leaves the patients with similar experiences, rather they diverges. In personal telling of illness stories by patients they gain the upper hand. On constructing such narratives they do an intense research into their sense of self and thus profit deep insights of life. Although chronicling these experiences illuminates both the narrator and the reader, they are so far considered as paranoid. This project attempted a study on tracing the reparative traits of quest narratives *When Breath Becomes Air* by Paul Kalanithi and *The Cancer Journals* by Audre Lorde, and thereby observed how the transformation of self occurred through the articulation of personal lived experiences of illness. It also elucidates what these accounts offer for its readers. Reparative reading and writing practices as explicitly offered by Eve Kosofsky Sedgwick denotes where the practitioner is engaged in a process of repairing or reconstructing themselves by the acknowledgment of their diverse situation. Quest narratives, a type of illness narratives, a concept delivered by Arthur W. Frank conceptualize illness as a journey undertaken by the hero, who faces illness and its consequent realities head on. He also argues how telling stories becomes an act of resistance.

*When Breath Becomes Air* and *The Cancer Journals* are two groundbreaking life-stories on their respective encounters with cancer. Although, both narratives are engaged in

recounting cancer memories, they are distinct on their own. *When Breath Becomes Air* is a doctor-become-patient experience of Paul Kalanithi, a young neurosurgeon who at the apex of his life was diagnosed with stage four lung cancer. Kalanithi was engaged in a quest to have direct life and death experience and hence, he chose his career as a neurosurgeon, as a doctor. However, his unanticipated bumping in to cancer formulated the question - What makes life worth living in the face of death. The circumstances under which Kalanithi's perspectives initiated a transformation and the methods he chose subsequently to live a meaningful life frames the reparative attributes of his life and its literary depiction. Paul envisaged a delightful life ahead and promised a meaningful one to his wife. Shattering of his promised dream invoked a sense of fear in him. He was concerned about his career as a neurosurgeon, his planned fatherhood and his family. These were the social sufferings he endured. Physical pain propagated by the ascending cancer cells was no less when Paul felt his back bone rupturing pain. On an emotional and deeply intimate part he was reminded of his past identity. The doctor in him was untouched by the pain and sufferings of his patients, although he respected the self and identity of his patients. This piece of illness tale emphasises that repercussions of illness are experienced at different levels.

The reparative features of Kalanithi's narrative are patently visible when he decides to transform his life to a meaningful one. Paul was in his final years of neurosurgery residency period when he was diagnosed with cancer. He took a break, for he lost that confidence he had and his future blurred before him. In his quest for the meaning of human life he was certain that ultimate end of all organisms is death. Death is the only constant in life. Realization of death as the ultimate truth, made Paul to decide on living a meaningful life. As the first step he went back to hospital to complete his graduation and successfully finalized his graduation. On the day of his graduation, unfortunately his body became weak and he got hospitalized. However, he succeeded in consummating one of his dreams. He found himself

on those hospital rooms where he as a doctor discussed with his patients about symptoms and treatments. Paul and his wife Lucy contemplated on their parenthood. And Paul thought it would be better if Lucy has someone beside her in his absence to fill the emptiness. They had Cady, their precious daughter, who illuminated the final days of a man facing his mortality. Paul, apart from his profession of doctor, was immensely in love with literature and he also had a post graduation in English literature. *When Breath Becomes Air* is an embodiment of his passion for literature. In his hospital bed, with a fragile and feeble body and self Paul returned to literature in his meaning making journey. He vastly read all those books which he thought attribute meaning to death. Younger self of Paul desired to be a writer. When his body failed to respond to all phases of his treatments and brought him to an almost death experience, Paul was engaged in structuring and formulating this book.

Paranoid reading might highlight the possible atrocities, pain and loss associated with cancer in Kalanithi's writing and how he was privileged as a doctor to be fully aware of his medical condition and how feasible it was for him to endure the pain, fear and sufferings cancer for the same reason. However, reparative lens will provide another dimension that communicates how persistent and focused Paul was during his final few months dedicating himself to the completion of this book although it did not. Paul was indeed an enthusiastic person who searched for meaning of human life, who treasured literature. On the verge of death, on constructing this illness narrative Paul analysed his former self, acknowledged his fears and loss and faced his death gallantly. By recognizing his new reality and there by engaging himself in the meaning making process a transformation of self could be observed. His acceptance of death as a constant reality made his occupied to explore the meaning of death. Nevertheless, the transformed self of Paul was always part of what he already was. Fundamentally, telling his story was Paul's resistance to live an unworthy life in the face of death.

*The Cancer Journals*, along with Audre Lorde's illness experience elucidates the hidden politics behind the prosthesis for post-mastectomy women. Similar to the paranoid views analysed in *When Breath Becomes Air*, Lorde's account could also provide paranoid stances which might conclude her denial to prosthesis as unreasonable and imposing when some women would chose prosthesis. *The Cancer Journals* is a black lesbian feminist experience of cancer. Lorde's experience between the period of biopsy and a mastectomy was distressful for her. Her intimacy with her breast and the fear of its lose was unbearable. Her first biopsy was negative, yet she was frightened by the thought of a malignant cancer. Even in the absence of cancer she encountered with death. Thus, when her second biopsy turned positive she anticipated the possible pain, fear and loss that would accompany her breast cancer. Nonetheless, she was stunned by how much she contemplated on her decision of doing a mastectomy. For losing her breast was like separating from her mother. The pain, fear and suffering burdened her emotional, physical and social self. She was concerned for her job, her future, her pleasure and her family. She wondered if she could feel the pleasure same as before. She pondered in memories of her older self. Lorde subsequently arrives at the conclusion that losing her breast is worth to gain her life. The reparative attributes can be analysed prior to mastectomy as well as post mastectomy. Lorde perceives her fear and lose head on without concealing her emotions and proceeded to do mactectomy. Post mastectomy Lorde's uneasiness was around prosthesis. Lorde's deep insight she developed by evaluating herself allowed her to accept her scared body though she found it hard to accept while examining the images of amputated breasts. She strongly opines that she would unequivocally feel the distinction on wearing a prosthesis and denies the comment 'no one will know'. Lorde illustrates how the consumerist society of America is busy objectifying women. The media, prosthesis developing industries and plastic surgery industries urges women to conform to the beauty myths associated with women's body. They programme

women by injecting ideas that breasts are essential for them to look beautiful and thus giving emphasis to the appearance of female body. Lorde does not restrict women from using prosthesis, but she questions its use coming out of an imposed necessity and not from self-evaluated decisions. On sharing her experience Audre Lorde formulates a resistance to society that imposes stereotypical images on post mastectomy women by restricting their space for a self evaluation. Lorde in writing this piece of narrative undergoes a transformation of self when she revisits her past encounter with death. On the brink of death, she insists, what matters is survival and not mere appearance

Why is it relevant to read lived experiences of illness? And, what does it offer to its readers? Both *When Breath Becomes Air* and *The Cancer Journals* vividly answer these questions. Both Paul Kalanithi and Audre Lorde when diagnosed with cancer were bombarded with distinct kind of thoughts. Paul found his solace in literature. He had experiences as a doctor. Paul's interrogations were surrounded in meaning making of death and he immensely read all those writings which gave his answers, and that includes illness narratives as well. Audre Lorde looked around her for role models for a black lesbian feminist experience of cancer and eventually came to realize that she was all alone. These are the instances when shared experiences of illness will find its purpose. After her mastectomy Lorde engaged herself in conversing with post mastectomy women and thus sharing individual experiences of breast cancer. Her exchanges with Li'l Sister illuminate readers on different interpretations of cancer and its treatments. Moreover, both these narratives want to offer their readers other than symptoms, treatment and diagnosis.

Paul Kalanithi's narrative wanted its readers to make their life worthy of living when they are alive. Furthermore, it shares a lived account of how it is possible to come in terms with death with integrity. Audre Lorde teaches the significance of self-love and on constructing her illness narrative she intended reach those who are in need of such a shared



experience of fighting with breast cancer. When Lorde searched for such a companionship, all she received was her loneliness. If tomorrow anyone else reaches for it they will find Lorde's account or any other such lived experiences of illness for their comfort.

## Work Cited

- Bernard, Emily. "Audre Lorde Broke the Silence." *The New Republic*, 25 Mar. 2021, [newrepublic.com/article/161595/audre-lorde-warrior-poet-cancer-journals](https://www.newrepublic.com/article/161595/audre-lorde-warrior-poet-cancer-journals). Accessed 22 September 2022.
- Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life Writing*. The University of Wisconsin Press, 1997.
- Ellis, Danika. "The Danger And Necessity of Paranoid Reading." *Book Riot*, 14 Oct. 2021, [bookriot.com/paranoid-reading/](https://bookriot.com/paranoid-reading/). Accessed 14 August 2022.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness and Ethics*. The University of Chicago Press, 1997.
- Gay, Roxane. "The Legacy of Audre Lorde." *The Paris Review*, 17 Sep. 2020, [www.theparisreview.org/blog/2020/09/17/the-legacy-of-audre-lorde/](https://www.theparisreview.org/blog/2020/09/17/the-legacy-of-audre-lorde/). Accessed 25 August 2022.
- Jurecic, Ann. *Illness As Narrative*. University of Pittsburgh Press, 2012.
- Kalanithi, Paul. *When Breath Becomes Air*. The Bodley Head London, 2016.
- Lorde, Audre. *The Cancer Journals*. Spinsters/ aunt lute, 1980.
- Maslin, Janet. "Review: In *When Breath Becomes Air*, Dr. Paul Kalanithi Confronts an Early Death." *The New York Times*, 6 Jan. 2016. [www.nytimes.com/2016/01/07/books/review-in-when-breath-becomes-air-dr-paul-kalanithi-confronts-an-early-death.html](https://www.nytimes.com/2016/01/07/books/review-in-when-breath-becomes-air-dr-paul-kalanithi-confronts-an-early-death.html). Accessed 15 September 2022.
- Nole, Leonardo. "Every Cancer Narrative Is an Act of Life: A conversation with Nancy K.

Miller.” *Other Modernities*, 2020, nancykmiller.com/pdfs/nancy-k-miller-leonardo-nole-every-cancer-narrative.pdf. Accessed 19 September 2022.

P, Jinoy Jose. “The real art of living.” *The Hindu Business Line*, 20 Jan. 2018.

[www.thehindubusinessline.com/blink/read/the-real-art-of-living/article8418522.ece](http://www.thehindubusinessline.com/blink/read/the-real-art-of-living/article8418522.ece).

Accessed 22 September 2022.

Sedgwick, Eve Kosofsky. *Touching Feeling: Affect, Pedagogy and Performativity*. Duke

University Press, 2003, pp. 123-151.

Sontag, Susan. *Illness As Metaphor*. Farrar, Straus and Giroux, 1978.

Spector, Rosanne. “Paul Kalanithi, writer and neurosurgeon, dies at 37.” *Stanford Medicine:*

*News Center*, 11 Mar. 2015. [med.stanford.edu/news/all-news/2015/03/stanford-](http://med.stanford.edu/news/all-news/2015/03/stanford-neurosurgeon-writer-paul-kalanithi-dies-at-37.html)

[neurosurgeon-writer-paul-kalanithi-dies-at-37.html](http://med.stanford.edu/news/all-news/2015/03/stanford-neurosurgeon-writer-paul-kalanithi-dies-at-37.html). Accessed Date 26 August 2022.

Woolf, Virginia. “On Being Ill.” *Medicina Narrativa*, 2016,

[www.medicinanarrativa.eu/wp-content/uploads/2016/11/Virginia-Woolf-On-Being-](http://www.medicinanarrativa.eu/wp-content/uploads/2016/11/Virginia-Woolf-On-Being-Ill.pdf)

[Ill.pdf](http://www.medicinanarrativa.eu/wp-content/uploads/2016/11/Virginia-Woolf-On-Being-Ill.pdf). Accessed 16 August 2022.