

LIFE WRITING: MONOGRAPH SERIES
SERIES EDITOR: G.S. JAYASREE

**LIFE-WORLDS OF
CANCER:
NARRATIVES THAT
RESIST AND HEAL**

Bini B.S.

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Institute of English
University of Kerala, Thiruvananthapuram

**Life-worlds of Cancer:
Narratives that Resist and Heal**

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Life-Worlds of Cancer: Narratives that Resist and Heal is an inquiry into the narrative impulse generated by an extreme experience such as cancer, its harrowing treatment procedures and ruminations on impending death. Narratives, while acting as a coping mechanism, instrument for personal healing, or a site for sharing and empathy, also become a way of addressing larger questions concerning healthcare, medical ethics, justice and cultural attitudes and anxieties. The narrative journeys covering the vastly diverse domains of the corporeal and the social in this study turn into a powerful critique that exposes social prejudices, stereotyping and insensitivity around illness, proclaiming the power of writing as a force for change.

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Introduction

In our lives, illness is an undesirable and somewhat unpredictable presence; so are injuries and disabilities. Human beings have suffered permanent and temporary damage to their bodies and experienced how their selves are touched and transformed as a result. Serious illness, injuries and disability create a scenario in which our independence is under threat as we may be forced to reach out to the members of family, friends, medical professionals and many others in search of solace and support. The body communicates illness in terms of changed appearance and visible symptoms. Even then, a person who goes through the experience of illness is required to narrate it, especially to healthcare professionals and dear and near ones. Though illness is a dreaded phase of existence, it may compel a person to establish more meaningful and deeper connections with oneself and others.

The uncertainties and confusion that descend upon oneself with the onset of disease sometimes fuel and spark narrative impulses. One who is 'terminally' ill tells stories to oneself and others, being confined to the trauma of a present which does not promise a future. Arthur Frank observes in *The Wounded Story Teller*, "Those living in chaos are least able to tell a story,

because they lack any sense of a viable future. Life is reduced to a series of present-tense assaults. If a narrative involves temporal progression, chaos is anti-narrative” (xv). Still, the ‘tense’ present may erupt in stories so that the chaos of life can be contained in narrative and meaning; a dream of order to dare the unruly nightmare of illness. Besides, a narrative that transforms transient life to the relative permanence of text, defies death by invoking the kind of immortality we usually attribute to the written word. In this study, I have used texts that partake in the narrative urge that illness sometimes generates. I am in no way suggesting that illness, by default, has a fierce pedagogy full of lessons of life and weighty philosophical insights. Nor does illness consistently urge one to tell a story. The narrative and philosophical facets of being ill are not universal, but one of the many possible responses to it.

Narration, oral and written, is useful as an interpretative exercise which contributes to curing and healing in multiple ways. One aspect of narration is elucidation for helping others catch a glimpse of the self’s vast experience. Letting the other into the territory of the experience of the self is important for reasons numerous. Without such an effort, a patient cannot make the medical professionals and caregivers understand the complex signs of illness inscribed on the layers of the self that even sophisticated mechanical diagnostic devices cannot bring to light. Speaking about one’s body and illness is a cognitive and affective procedure. It might be through narrating an illness to oneself and others that the person who is suffering from it tries to analyze, bring some coherence into, negotiate, reason out and deploy the strategies for dealing with one’s condition. Most importantly, narrative practices provide assistance to the patient in understanding and accepting one’s own altered self and altered life.

Subjectively describing one’s illness to doctors, nurses, other healthcare professionals and caregivers is one of the many aspects of illness narratives. It is also a way of telling the story of one’s life with an implicit hope that such a narration would help the expert in finding the path to a possible cure. But the scope of illness narratives is not limited to such a utilitarian intent. It is not a simple explaining of the symptoms of some disease

that one's body feels, to those who can treat it, alleviate the difficulties associated with it or uproot it. Narration is not done merely to seek a remedy so that the body is restored to a state of functionality, energy and wellbeing. Telling stories about one's own or another's illness can be a layered narrative practice with aesthetic, socio-cultural, political and ethical significance.

Illness is a quagmire that sucks one deep into the body-self; sometimes it is also an occasion to form new associations with the world. This study focuses on cancer narratives by eight women writers who venture into and beyond their corporeal selves to map journeys of illness, one's own or another's. These narratives call for a re-vision of the notions of the subjective, the corporeal, the experiential, and the social in the fields of medicine and healthcare. The narrators provide wide-ranging vistas through the lenses of gender, race, sexuality, and class, merging together numerous perspectives into kaleidoscopic and multifocal stories of illness. The narrative journeys of pain, fear and suffering, sometimes with death looming large in the horizon, could expand to explorations of the self and the world and even a universe of profound meanings. There are moments when the narrators rage, complain and feel dejected and defenseless; there are also moments when they find joy, hope, peace and fortitude. Four of them - Audre Lorde, Gillian Rose, Susan Gubar and Eve Ensler - have written about their own experience of cancer. Susan Sontag has used her cancer as a launch pad for exploring the linguistic, figurative and socio-cultural territories bordering illness. Three other narratives are by women reflecting on the cancer of their dear and near ones: Simone de Beauvoir's narrative about her mother's cancer, the novelist Sigrid Nunez writing about the life and last days of Susan Sontag, her partner's mother who died of cancer and Barbara Kraft's memoir about Anais Nin's cancer and death. These narratives survey the intimate topographies of body and illness to map the possible approaches to arrive at an understanding of the multifaceted self and its habitats. Such narrative exercises flesh out powerful notions about the body-self and stretch the limits of gendered corporeal identity and agency. I also refer to certain other cancer narratives in the study, though only the texts by the authors mentioned above are subjected to intensive analysis.

Disease and Narrative Impulse

Many cancer narratives have touched me deeply for a variety of reasons which motivated me to engage with them through a meta-narrative exercise; hence this narrative-analysis about narratives of illness. My research is based on a close reading of written narratives and also several interviews with women who have experienced cancer. For the monograph, I have used the narratives of 8 women, though my views were informed and influenced by the interviews I had conducted. While portraying erratic shifts and phases of cancer, the authors of these published narratives have been able to tear open the shroud of timid silence in which the body-self of women have been wrapped tight. Their narrative practices rebel against the attempts for hushing the voice of the self and assert the idea and practice of agency through writing. The texts selected in this study exude courage and integrity and do not shy away from freely expressing the fear, doubts, fretfulness and angst of the authors in the face of illness. The authors' concerns about the rights and fair treatment for women's bodies while they suffer from illness make these texts examples of how life writing turns into a form of interpreting and critiquing society and its institutions. These texts illustrate why and by what means life writing can be a meaningful mode of intervention and negotiation.

It is not unusual for illness narratives to come across as somewhat hesitant, uncertain, fragmented, and struggling to find ways to handle excessive emotional turmoil. They can also be assertive and aggressive, full of seething indignation to inhuman, unfair and inefficient treatment of the ill. Narratives about lived experience of illness and life worlds around illness can also suggest strategies for amendments and improvements in the functioning of the healthcare system. Narratives permit a glance into how thinking, feeling and responding human beings deal with illness. Moreover, coping with illness, disability and injuries may have a powerful impact on one's personality, social self, and attitudes.

Someone asked me why the term illness narrative has been used in the study. Can't it be healing narratives or wellness narratives? Such questions come out of a normative notion about what

direction the life writing about the experience of being ill should take. The publishing industry has created a demand for wellness and healing narratives of positive thinking, perseverance, courage and stoic suffering around illness. Every kind of suffering is not met with fearlessness and grit and does not lead to healing and wisdom. That is to say, narratives about hopelessness, stories that do not contain the formula for optimism and morbid tales of fear, cowardice and helplessness are not at all accepted or appreciated. Personal histories of illness that lead one to the realization that neither healing nor cure could easily be accomplished may fill a reader with fear rather than hope. I retain the term 'illness narratives' because that is what many of these narratives are about. There are narratives about being sucked into the whirlpool of illness and unable to swim to the shore of wellness. Illness narratives that rage and grieve and do not reconcile with the self and the world may not be inspirational. But such modes of responding with illness are also genuine and human and hence merit a thorough engagement.

As the old saying goes, an illness that does not kill you may make you bolder and stronger. But there is another side to it. An illness that leaves you un-dead may change you into a bitter, disillusioned and even meaner person; it may redefine your equations with your own body-self and notions about relationships with others. Sometimes a crisis discloses the 'true colours' of oneself and others. An illness may also mellow down a person; make her or him more humble, grateful and appreciative of life's little pleasures. It is unjust to insist that only a conformist 'standardized' response should come out of those who go through illness. There are many kinds and degrees of illnesses, disabilities and injuries. There is also a vast variety of people who experience illness. It does not make sense to expect an ideal pattern of response and resistance to illness from every human being.

A crisis may lead to new connections and attachments: the proverbial unity and solidarity that one finds in adversity. Each one who survives an excruciating illness may have to part with material wealth because quality treatment options for serious ailments are quite expensive. At the same time the person may gather considerable wealth of experience and practical wisdom.

The pedagogy of illness, injuries and disability can be so rich and varied. Each one learns from illness and shares the knowledge thus gained differently. Memories of illness are far from being pleasant, often packed with episodes of pain, humiliation, discomfort and anxiety. Still it is worthwhile to revisit and record these difficult times, since strong emotions may etch themselves on the personality of those who experience them. Revisiting the memories of sorrow, fear and pain may help one in tracing the transmutations in oneself.

What undergoes a sea change in illness is the terrain of everyday life, which often gets disrupted. It is not easy to comprehend illness and its multiple manifestations. It is even harder to find a suitable idiom and tone to speak of one's own or a dear one's illness. Representing, discussing and giving an account of illness are done to address many-sided communicative needs. As I had mentioned earlier, the most common narrative of illness is addressed to medical professionals. A person may be required to give an elaborate picture of one's illness to doctors and other healthcare professionals. Medical professionals are trained to know illnesses through symptoms that manifest physically in the patient, with a clinician's objective eye for relevant details and methods of diagnosis. Even then, patients may want the doctors and other healthcare professionals to know illness from the subjective perspective of those who suffer from it and suffer because of it. There are many dimensions of an illness – psychological, social and cultural – like the stigma associated with it or what it does to one's professional or erotic life. The experts may not consider any extra-physiological aspect to be relevant for diagnosis and cure. But such details are important if the doctors and other professionals engaged in prevention and cure of ailments pay more attention to healing and wellness. In short, when there is a shift of focus from treatment and cure in a narrow sense to such complex considerations as healing and well being with layers of practices and meanings embedded in them, willingness to engage with patients' narratives becomes increasingly imperative. Openness to patients' narratives which are more than pathographies could be the first step in a healthcare professional's adventure of healing.

There are individual and collective communicative efforts and forums intended for conveying the patient's discontentment with the products and services used for treatment so that the healthcare professionals are not allowed to remain indifferent to their own accountability and responsibilities. A patient may want to discuss the problems and inconvenience s/he faced during diagnosis, treatment and post-treatment-follow-up procedures. This kind of a feedback would shock the healthcare professionals out of complacency. 'Cure' is given undue emphasis in healthcare. Doctors believe that if an illness gets cured, the hardships and injustice one had faced on the path to cure become irrelevant and are not worthy of being mentioned. But there are patients who feel strongly that all is not well that ends well. They want to talk about the difficulties they endured so that those who access healthcare services in future may have a better and improved experience. Hardships and trauma may have left deep scars in the flesh of their psyche and become part of their self. So even if the woe of illness is a thing of the past, its memory remains raw and hence much relevant to the present, however symptom-free one's body is. Often life writing based on illness is meant to be addressing the healthcare industry in general as many patients and caregivers write with a specific aim of expressing their lingering grievances. Patients may also want to share first-hand knowledge of living with illness. Narratives that openly discuss the inadequacies and shortcomings of healthcare personnel, products and services are to be appreciated because many would benefit from such accounts by being more wary, conscious and informed.

In the studies about life narratives, we see an overlap of humanities and social sciences as an auto/biography, fiction inspired by journeys of life and layers of life-worlds captured by other forms of life writing contain many epistemological and experiential dimensions. The narrators are also multifaceted beings who have more than one reason for writing their stories of life. The narrative turn in healthcare and medicine is an outcome of widespread dissatisfaction with the rather impersonal and coldly analytical/ rational methods of diagnosis and treatment which had been followed for many centuries. Doctors and

healthcare professionals and even patients find the detached and rational clinical approaches that do not give much scope for communication to be limiting and narrow. Narrative practices try to bridge the gaps between different levels and kinds of stakeholders of healthcare. That is to say there are gaping chasms of incommunicability between governments, medical professionals, administrators of hospitals and other institutions for healthcare, patients and caregivers. Narratives have the power to break into and reach out to domains of exclusivity, facilitating understanding, reciprocity and fellow feeling. Narrative practices, especially life writing on illness help in making the approaches to illness more humane and less mechanical and detached. Narrative practices enrich the arts of empathy and 'interpathy' or the self's purposeful and purposive cognitive and affective envisaging of the thoughts and feelings of the other, with an acknowledgement full of humility that the life world of the other is not fully accessible. Life writing on illness encourages multi-directional communication, respect, responsiveness and reception of the other as a sentient being.

Narrative practice based on illness refers not only to written or spoken words which are meant to be read, heard and reflected upon. Though this study is limited to auto/biographical texts by women, illness narratives may comprise other media for expression including paintings, sculpture, performances, film and visual representations such as graphic-auto/biography, comic strips and the like. Narrative thinking and practices are not confined to the literary, linguistic and semantic realms. Many forms of expression which facilitate communication of ideas and emotions by telling a story from the point of view of one or many narrators can loosely be described as a 'narrative. One can tell the story of oneself through writing it down as a journal or work of fiction. But it is just one of the many ways. A work of art and perhaps even dance and music may become handy in narrativizing the self, its complex modalities of embodiment including the experience of illness. This study focuses only on written and published narratives about illness. Illness narrative as life-writing may have a single author, but that narrator "I" contain multitudes. Thus life writing based on illness can weave together

countless voices and numerous narrative threads. In *Narrative Research in Health and Illness*, the editors make this observation:

Polymorphous in content, malleable in form and dynamic in expression, narratives are compositions of unfolding meanings which can be discerned and followed by an audience. Narrative thinking and imagining therefore embody temporal and causal frames of reference manifest in myths, cave art, fables, fiction, and drama. *Closely synonymous with humanity itself, narrative capabilities such as imagining, hypothesising and plotting have offered marked evolutionary advantages to humans over thousands of years.* (1; emphasis added)

In illness narratives the domains of the private and social can coexist in quite radical ways. Writing the body and about the body could mean a contemplative engagement with the domain of the self and its myriad lives and contexts. Such an involvement may be the first step towards affirming one's corporeal rights and justice. Narrative engagement with oneself or another is not an inconsequential feat as it may open the conditions for a strong agentiality to patients, especially women, enabling them to voice their views to challenge and surmount the taboos and prejudices surrounding their body-self. Writing about oneself and one's experiences can turn into a springboard for initiating discussions on matters which are important to many other human beings who get a chance to reflect upon and reconstruct their own experiences of a similar nature in the light of what they read. Moreover, writing the self and writing about the self can accomplish more than being metaphorically confessional and redemptive for the self. These acts are not limited to some sort of emancipatory healing reached through retelling the self's story of suffering from an illness. In a very broad and general sense, illness suffered by the self turns into a metaphor for social ills and writing may transform into a means for diagnosis and healing the ills of the society and its institutions. Writing about illness thus becomes instrumental in dealing with ailing healthcare institutions and services in such a way that an awareness enabling their healthy functioning is created. By making the patients' perspectives available to healthcare professionals and administrators, the

domain of healthcare can be made more efficient and humane to suit the needs of patients who are its beneficiaries. Widespread narrative practices can help in facilitating beneficial decisions about healthcare policies and patients' rights. I am in no way suggesting that narratives of illness should have a stated or subtle aim of creating awareness and effecting social change. Narratives do have a power to challenge and resist injustice and assert the rights of the narrator; but that is one of the many possibilities of narrative practices.

Utility of narrative exercises for promoting beneficial practices and minimizing harm is not a utopian dream. But it is not something easily accomplished. There are times when a patient discovers one's urge and courage to tell the truth. Someone's claims to truth is determined by the degree of her/his access to power and for this reason, the utterance of truth about illness has always been monopolized primarily by presumably knowledgeable professionals. The tutored and trained professionals are seldom willing to listen to opinions and criticisms from the supposedly 'ignorant' patients' perspectives. Now that the locus of power is shifting towards the vast territories of patients' life-worlds, as an outcome, the idea of truth in healthcare and medical profession has become more multi-logic rather than monologic, multiple rather than singular, diverse rather than unitary and subjective rather than objective. Healthcare domain is now more willing to accommodate varied and nuanced viewpoints based on lived experiences rather than ossified convictions built on clinical knowledge and training.

My study looks at life writing about illness as part of narrative medicine, defined as "narrative competence to recognize, absorb, interpret, and be *moved by* the stories of illness" (*Narrative Medicine: Honoring the Stories of Illness* vii; emphasis added). Narrative medicine is the meeting ground for humanities, narratology, social sciences and medical sciences and would be effective in establishing a more perceptive and sensitive link between doctors and other healthcare professionals and patients. Rita Charon, the author of *Narrative Medicine* elaborates:

When we human beings want to understand or describe singular people in particular situations that unfold over

time, we reach naturally for narrative, or storytelling, to do so. When we try to understand why things happen, we put events in temporal order, making decisions about beginnings, middles, and ends or causes and effects by virtue of imposing plots on otherwise chaotic events.... *By telling stories to ourselves and others — in dreams, in diaries, in friendships, in marriages, in therapy sessions — we grow slowly not only to know who we are but also to become who we are.* Such fundamental aspects of living as recognizing self and other, connecting with traditions, finding meaning in events, celebrating relationships, and maintaining contact with others are accomplished with the benefit of narrative. *A medicine practiced with narrative competence will more ably recognize patients and diseases, convey knowledge and regard, join humbly with colleagues, and accompany patients and their families through the ordeals of illness.* These capacities will lead to more humane, more ethical, and perhaps more effective care. (vii; emphasis added)

Narrative medicine is a vital and vibrant field of inquiry which is on its way to more critical and creative reflections and expansion. It is one of the many fields of study under the interdisciplinary–epistemological–experiential domain of medical humanities. The editors of *Medicine, Health and the Arts* try to explain the idea of medical humanities as a diverse and discursive field while admitting that the term is still being used in want of a better expression:

We take medicine to include institutional medicine, health and well-being of the mind or body; the humanities to include history and the arts; and the methodologies for studying the medical humanities to include examining theory, practice, impact and representation. Indeed, the definition of humanities taken here could be expanded much further. (5)

The conceptual, methodological and theoretical bases of narrative practices focused on illness and healthcare are constantly being questioned and reconstructed. The work put in by healthcare professionals, creative writers, scholars of literature,

artists, anthropologists, sociologists and historians to widen the scope and reach of narrative medicine is commendable. Narrative medicine is an interdisciplinary and multifocal field wherein conceptualization is largely based on life-worlds, interpersonal relations and uninhibited exchange of ideas and emotions through myriad media of expression and interaction. It is a field where the epistemological-theoretical-conceptual and the experiential meet and enrich each other. Though I would prefer terms like 'narrative practices in healthcare' or 'narrative wellness' rather than 'narrative medicine', I am in support of the aspiration behind the idea. I also deliberately avoid the term pathography and stick to narratives of illness or illness narratives, with a conviction that narratives of illness are not restricted to telling the tale of a disease. They have an underlying impulse towards rediscovering the self. Narrating one's illness may be an opportunity to express one's horror, anger, pessimism, fear and bitterness unequivocally. An Illness narrative can also be a narrative of wellness and healing, about coping, coming to terms with and reconciling with illness.

Clinical practice as a human science faces a dilemma: the choice between the *singularity* of an individual's personal experience and the *generality* of anatomical structures and physiological functions of the *homo sapiens* as a species. Narrative medicine affirms that assimilating the singularity of the individual with the generality of the species is certainly possible and desirable. Narrative practices establish that there is no rupture between the singular and the general; both enlighten each other through the act of story-telling. The compulsion favouring objectivity should not smother the still stronger urge for subjectivity. Both can be integrated in narrative exercises for a deeper and vaster understanding of illness and the self. Those who endure illness as well as those who try to cure illness would benefit from joining the forces of the singular and the general. It is also worthwhile to blend the subjective and the objective in a more fluid discursive grid of illness-body-self.

The human body as a site where the disease originates and spreads is not the only site where the management of disease is concentrated. Whatever happens to my body is an incident in

my life and it touches the layers of my 'self' and 'being' at large. The social constructions of both self and illness should not be subsumed under an anatomical-physiological understanding of illness that clinical training usually produces. Varied narrative constructions of the self and inquiry into the processes through which the self is constituted, contain a rich pedagogic opportunity for healthcare professionals. Self as a narrative, dialogic and performative site would provide various occasions to think around many pertinent issues concerning social and psychological life of human beings. Narratives based on life and life worlds may open the doorways for entering into the inner, social and professional lives of patients, doctors and other healthcare professionals, which is very important for all the stakeholders of healthcare. Howard Brody has a perceptive take on the dream of integrating the personal and the general:

To deal with the part of medicine which treats everyone as the same, we must extract the narrative from the patient and recast it as a "case history" or as a medicalised retelling of the story. If we do not do this we can never bring to the patient the undoubted benefits of modern medical science. If we do only this, we dehumanise the patient, fail to address him or her as an individual, and ultimately may very well increase the patient's suffering.¹

Human to human engagements are facilitated by a narrative exercise as it reconstitutes the mode of addressivity. As discussed before, narrative practice combines an involved and person-specific perspective with impersonal and generalized epistemology that would influence clinical practices. Narratives engage with the individuality and idiosyncrasies of each person and directly talk to the intended reader by addressing her/him as a fellow human being. For someone who writes about one's illness, the potential readers - others who go through a similar plight, medical professionals or healthcare administrators - are all fellow human beings who may *understand* the syntax and semantics of the disease and the self which suffers from it. Understanding is not instinctual; it requires willing involvement and conscious effort from the other. It can be more or less intuitive at times. There is little scope for aloofness and reserve in a narrative practice

aimed at reciprocal understanding. Direct communication with medical professionals may not be free from the prevalent forms of control over knowledge and speech. The right to express and be heeded is determined by age, education, profession, gender, class, race and region. These modalities for controlling speech and expression are similar in process to the power equations and patterns of domination that are operative in society at large.

As I have mentioned earlier, narratives of illness used in this study exemplify speaking truth to power. Medical professionals may exercise their authority emanating from expertise and professional knowledge. Their relative inexperience and lack of knowledge in medical matters may partly silence the patients about their illness and prevent them from voicing their fears and apprehensions openly. Though the doctors and medical professionals are becoming more receptive to the narratives of the patients even if it means surrendering their monopoly over interpreting illness, there are still many daunting problems to be addressed. It is not uncommon that the patient's story is consumed by the medical story, and digested into a different version of depiction and meaning. Patient's story gets emptied, appropriated and retold. It is to prevent such appropriation that patients are encouraged to create their own versions of stories loudly and clearly to address not only medical professionals, but also patients or caregivers who are seeking solace and lessons from experiences of illness comparable to theirs.

Scholars like to believe that the domain of life writing can possibly offer a degree of epistemic authority that lived-experience provides. I have great respect for the voice of experience. Still I sometimes find it problematic when the truth of experience is celebrated as 'The Truth' which is incontestable. It is assumed that the self is the most qualified entity to speak about its own experience. But the self's perspective may be coloured and shaped by factors that the self does not understand, have control over or even know about. The self cannot access every layer of its own experience; nor can it interpret and make sense of all nuances of experience which are so diverse and complex. For that reason, integrating the views of others into the interpretation of the self is not to be dismissed as a compromise, falsification

or contamination. The other is not roped in for validation or justification, but for providing alternative points of view from a fellow human being's equal grounding. This would help in challenging the smugness of the self who assumes the role of the author of its own supposedly authentic story. The self cannot always see its face, but reflections of itself in the eyes of the other.

Gone are the days in which social sciences looked down on fiction and autobiography. There was a time when these genres were considered too subjective to be true to facts. Now we recognize objectivity as an impossible condition because all knowledge is mediated by the knowing subject. As a result, narrative writing in its various roles - as intervention, mediation and representation - has been recognized somewhat reluctantly by social sciences. Another point I want to emphasize in this context is that the existing standards for validating narratives of life and lived experience seem so pointless and dated. Authenticity, verifiability and neutrality are narrative values which exist in the plane of the ideal and have very little to do with actual narrative practices. I do not mean to suggest that life-writing based on illness has to be read as make-believe, dramatization of crisis, work of imagination and untruth. We need to ask different kinds of questions about life narratives on illness.

The self is a story that has not yet been fully told because it evolves and changes continuously. With its fluctuating plots and fuzzy mode of characterization, it remains unpredictable and resists closure and finality. Self is both created and elucidated through writing. Does the act of narrating the self and engendering its stories result in dissipation of the self? Identities are constructed and transformed through narratives and copious and capacious are the identities of the self hence engendered. Narrative practices are not limited to an act of mimesis and representation. Narratives of the self often reformulate the notion of identity itself. Do narrative practices like recollecting, re-membering and recording one's identity through telling its story call for apprehensions about a likely forgery of the self? The self may get fabricated and turn into a fiction on being narrated. Though the idea of an 'accurate self understanding' seems so passé, Galen Strawson's critique of narrative practices is still worth considering:

... the more you recall, retell, narrate yourself, the further you risk moving away from accurate self understanding, from the truth of your being. Sartre is wrong to say that storying oneself is a universal trait, but he's right that it is extremely common, and he is surely right, contrary to the tide of current opinion in the humanities, that the less you do it, the better. (qtd. in *The Self in Health and Illness* viii)

We must distance our minds from futile queries and apprehensions about degree of truth, amount of credibility, measure of authenticity and techniques for distinguishing between fact and fiction in narratives of illness. If the interpretative focus is shifted to more substantial issues such as context(s), politics and mechanisms of representation, strategies for selection and omission, deployment of ideas being communicated in the text, grey and silent/ silenced areas in the story and texturing of the stories of illness which are woven into the narrative web of a life-story.

Setting out on a narrative journey during illness is not to be dismissed as a narcissistic or self-indulgent exploration. Narratives have expanded the journeys of the self beyond the limited scope of the anatomical atlas while experiencing an illness. What one calls an experience is about feeling and knowing and remembering and narrating as much as about living or going through something. Experience is about being present in something and representing that something. It could be an incident or a happening, a perspective, a result of retrospection or a construction resulting from analytical, imaginative and interpretative process. An illness narrative may deal with many-sided, disconnected and discontinuous multiplicity of experiences. The narrative self is the 'me-multiple' which attempts to immerse in the flow of events. In the process, the self is continuously undone/ re-shaped/ fluctuated by what it experiences. Identities are usually defined by many frames of reference including gender, class, region, religion, ethnicity, race, caste, sexuality and state of health. Illness, as an unanticipated and abrupt force of change, can unsettle and put back these identities together in an altered format or render them irrelevant. Narrative practices can be called for assistance to handle the commotion and crumbling of the self.

But, narrating about illness, injury or disability is not restricted to an urge to hold the scattered pieces of oneself together against the fragmentation one encounters. Writing about the self that suffers from illness is about developing receptiveness and forming links. It may be a struggle for coming out of the torture chamber of oneself to enter into a dialogue with others who are also suffering from painful or life-threatening illness.

Life writing based on illness provides a glimpse into what patients and caretakers endure, to medical practitioners who may then be motivated to take a stance of less condescension and more empathy. Medical practices, if enriched by such narrative practices as reading, researching, analysis, writing, telling and listening to stories of experience and reflecting on relevant issues, would benefit immensely. The field of medicine, which is becoming highly commercialized, corporatized, mechanical and inhuman, may rediscover values of great import that are now on the wane. Empathy, accountability, sensitivity, humility and compassion can be built into medical practices if narrative practices are integrated into it. Patients' narratives compel the doctors to acknowledge them as active thinking-feeling-communicating individuals rather than passive sick bodies at their mercy. Moreover narratives of illness can provide a critical view about the fraud, unaccountability, corruption, commoditization, greed and obsession with profit-making prevalent in the present healthcare industry from the point of view of the consumer.

Many steps towards quality assurance and improvement in highly competitive healthcare industry had been taken in the new millennium, which include enhancing the communicative and interpersonal skills of medical professionals, educating healthcare professionals in gender and culture sensitivity, encouraging team-efforts of various specialists in diagnosis and treatment and providing expert training in conscientious professionalism. Narrative efforts by patients would pave the way for meaningful patient-centered care. In narrative practices, there is a latent opportunity for pointing out where the healthcare industry and medical profession fail to fulfill the expectations of beneficiaries. Collective narrative activism through advocacy and support groups, blogs, vlogs and books by patients and care givers, telling

the stories of illness through visual and social media and the like continue to positively impact the policies and decisions of governments and healthcare administrators. For ensuring justice, fair treatment, equity, dignity and protection from negligence and fraud for those who seek medical care, narrative activism has the potential to play a powerful and important role.

Narrative practices have been instrumental in making reassuring changes happen in how patients are viewed and cared for. The *modus operandi* of doctors, nurses, other medical support staff and social workers would experience a major improvement if their concepts of work, duties and work-ethics are supplemented and reinforced by insights from patients' and caregivers' narratives. Life narration is gradually expanding its space in clinical practice as doctors and others working in the field of healthcare are eager to engage more assiduously with narratives for their own good. Narrative practices in the domain of healthcare promote attention to ethical care by enabling open and free-flowing communication based on equality and mutual respect and ensuring quality of life rather than prolonging burdensome existence of pain and suffering.

The discursive and dialogic potential of illness narratives opens a channel for intersubjective exchanges and answerability, which in turn would influence modes of engagement with issues of power and ethics. The ideas of justice and ethics in the domain of healthcare would benefit if the practice of ethics and justice are not dependent on moral codes ossified in objectivity and universalism. If justice and ethics could be understood and practiced more fluidly and in an open-ended context-sensitive way, the domain of healthcare would definitely benefit. That is to say if we have a notion of justice and ethics as constantly evolving practices which are informed by everyday lives and individual experiences, that would be quite promising. The narrative domains of experience, language and expression, and epistemological as well as discursive practices associated with them constitute a rich and varied understanding of the everyday.

One of the factors capable of making possible a system of healthcare that acknowledges human to human relation between

service providers and beneficiaries would be narrative practices. Then the care extended to patients transforms into something more than a professional duty or business interest. Conscientious and ethical professionalism demands proficiency in the job of prevention and cure of illness; but that is not everything. Treating the ill as human beings and not as damaged goods requires a considerate and unassuming approach from the doctors. Developing the skills of unthreatening and reassuring interactions with patients is another area that doctors may want to educate themselves in. An unprejudiced perusal of narratives would come handy in such efforts of doctors who aspire to transform themselves from curing machines endowed with technological skill into sensitive human beings trained in the art of healing.

Narrative practices for health address diverse problems, yearnings and demands and play a pivotal role in tying together and making sense of crucial aspects of healthcare. By honouring the stories of illness, healthcare professionals' understanding of body-self, with its complex mechanisms and experiences of pain, disabilities, ageing and dying would change from a limited clinical view on body to a much broader socio-political, gendered and cultural perspective on embodiment. Embodiment is performative and a process where the body is being looked at as a boundless entity of multiple parts and functions.

The stories people tell themselves and others constitute a people's understanding of themselves. Stories also explicate and interpret the self's terms of engagement with others who share space and time with oneself. That is why stories are integral to initiating and giving momentum to social movements. There is no absolute divide between the social and the personal in life writing. In generating a collective awareness for collective benefit, shared stories play a vital part. Such collectivities and solidarities generated by shared experience of illness are not usually coerced. Stories of illness create contexts and conditions for the formation of strong ties based on equality and reciprocity. Collective groups with certain common concerns and aspirations in turn lead to collective action with a shared purpose. Narrative

practices focusing on the experience of illness form an informal community of people unified by similar and interconnected aims and objectives. Auto/biography and collective action are thus allied in complex ways. The texts that I have selected for this study explore the possibility of auto/biographies getting translated into a clarion call and shared desire for collective action.

It is important when the illness narrative is being written: during the experience of illness or in retrospection. One's views on experience change as the distance in time varies. Engaging with the experience of illness while still in the middle of it and looking back at it as a thing of the past may give rise to different narrative practices and considerations. The 'I' in the autobiographical accounts about illness may be the kind of 'I' that a person as a narrator wants oneself to be. While constructing a narrative about the life of oneself and another human being, the narrator may be influenced by the notion of an ideal self. We all have been exposed to views on how a person should behave during illness. More than mere mimesis of the self, writing is both an ongoing construction and transformation of the self:

While representing the self implies a pre-given self that is expressed in the writing, *writing* involves a becoming of the self, a making of a self that is not already all of a piece, but, rather, is in process. In writing and in other practices, then, there is the potential for self-transformation (*Passionate Sociology* 103).

Courage in the face of adversity, optimism, confidence and uncomplaining acceptance of pain and discomfort are said to be the virtues of an 'ideal' patient, though it is difficult if not impossible to hold on to these virtues on being ill. The image of a selfish, self-centered, mean, inconsiderate, constantly complaining, cowardly, frightened, weak and moaning patient who cannot suffer pain or discomfort with fortitude is not what a narrator would want to project in the story of one's or another's illness. There are many aspects of a sick self that one looks back in anger and shame on recovery and then may want to forget completely. So narrators might not choose to incorporate such moments in memoirs of illness.

War is a metaphor used in the context of illness frequently. A patient who *fight*s the illness valiantly and bravely, treating the injuries of war on one's body as trophies is supposedly a true 'hero' in the story of illness. Such notions are potentially dangerous as the inability to put up a brave fight may fill up a person with guilt and a sense of one's own inadequacy. Life writing that depends on memories of illness may willfully forget or remember differently certain traits of the self or moments of suffering in which the self could not put on a brave face.

Life writing, especially by women when they write from the experiential domain of corporeality, has been interrogated continuously, and subjected to revision and remapping in attempts to define, make sense of and validate a particular form of auto/biographical writing. Speaking openly about one's body, its pleasures and sufferings, has long been looked down upon with contempt and suspicion. Body remains an intensely private domain for many and for this reason, exploring and mapping this territory through art and writing have met with resistance, prudish dismissal and censorship. The secrecy and silence surrounding the body are not restricted to literary, visual and artistic expressions of its desires and pleasures. Pain, suffering, 'disfigurement', 'disability' and such potentially unsettling corporeal experiences had seldom been encouraged to be shared in public through writing and art. Body is slowly making a painful egress from the closed and secretive cage of the private and entering into an assertive and combative field of the political. The fact that more individuals are willing to openly speak, write and give aesthetic expressions to those corporeal domains considered private is an encouraging sign though it has its own problems as well. To bear witness to scenarios in narratives wherein the corporeal straddles the political as well as the personal fills one with a sense of hope and power. The texts in my study explore the interfaces of the corporeal and the social and the political; spaces which are throbbing with insights gained from life worlds and lived experiences.

Audre Lorde (1934-1992), known popularly as the 'warrior poet' was an American black feminist lesbian writer and civil rights activist who died of breast cancer. Her *Cancer Journals*

(1980) and *A Burst of Light* (1988) take us through the experiences of her first cancer diagnosis, mastectomy, remission, recurrence and last days in the shadow of death. Gillian Rose's (1947-1995) work yokes philosophy and sociology as she reads into her ovarian cancer. Curiously her work in sociology led to many of her philosophical ruminations. Rose's *Love's Work: A Reckoning with Life* (1995), which obliquely deals with her virulent cancer, is a profound work of philosophy that accommodates the social in a sensitive way. Befitting her career as a philosopher-sociologist, Gillian Rose faces her illness with inquisitiveness and analytical inclination. She goes on to write *Mourning Becomes the Law: Philosophy and Representation* (1996) and *Paradiso* (1999), which were published posthumously. Susan Gubar (1944-), American feminist theorist and Distinguished Professor Emerita of English and Women's Studies at Indiana University is best known for the iconic texts, *The Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination* (1979; co-authored with Sandra Gilbert) and *Norton Anthology of Literature by Women: The Traditions in English* (1985; co-edited with Sandra Gilbert). On being diagnosed with ovarian cancer, Gubar wrote *Memoir of a Debulked Woman: Enduring Ovarian Cancer* in 2012 which is an inspiring attempt to gain epistemic command over a devastating and life-threatening ailment. Eve Ensler (1953-), the famous author whose play *The Vagina Monologues* (2006) is a noteworthy work of political theatre and clarion call for corrective action through performance. Ensler is also an activist whose work is dedicated to prevention of violence against women and nature. After being diagnosed with uterine cancer metastasized in the liver and undergoing arduous treatment procedures, she wrote *In the Body of the World: A Memoir of Cancer and Connections* (2013). The memoir uses the extended metaphor of the ailing female body subjected to extreme brutality to make a case for putting an end to violence against earth, environment and women. Writing the memoirs of their illness provided a context for engaging with vaster and deeper concerns for Lorde, Rose, Gubar and Ensler. By writing the self and writing about the self, they tried to write about the world and write to the world. There is also an implicit and often unstated dream of 'righting the wrongs by writing about the wrongs' in the narratives in this study.

Susan Sontag (1933-2004), a prolific author of novels and powerful essays, film-maker, critic, teacher and activist, did not write a conventional memoir about her cancer. *Illness as Metaphor* (1978) uses her experience of suffering from breast cancer as a starting point for setting out on a journey for investigating into the cultural, especially linguistic and semantic aspects of illness. In 1988, she wrote *AIDS and Its Metaphors*.

Other than the first-hand experience of illness through one's body and self, the study also includes works reflecting on another's illness from the points of view of a witness, friend, and caregiver. Many a time, an agonized observer uses the force of narration to overcome the overpowering sense of passivity and helplessness on being made to bear witness to or share the anguish of a dear one's suffering and dying. Simone De Beauvoir (1908-1986), French writer, public intellectual, one of the pioneers of continental feminist theory, social activist, novelist and philosopher, in her horror, pain and puzzlement on receiving the news of her mother's terminal cancer wrote *A Very Easy Death* (1964), a heartrending account ironically titled thus. She talks about the problems old age, loneliness and illness from the involved perspective of a caregiver and uses the text as a context to reveal the sad state of affairs in the geriatric medical care of her times. The American novelist, Sigrid Nunez (1951-) in her work *Sempre Susan: A Memoir of Susan Sontag* (2011) captures some moving incidents from the life of Sontag who is the author of the groundbreaking work, *Illness as Metaphor*. During her relationship with David Rieff, the son of Susan Sontag, Nunez and Rieff used to share an apartment with Sontag. Rieff has also written a memoir titled *Swimming in the Sea of Death: A Son's Memoir* (2008) about the recurrence of Sontag's cancer and subsequent death which will also be briefly discussed in this study. With her eyes filled with love, awe and pain, Barbara Kraft (1939-) looks at the dying light of Anais Nin, her friend, mentor and role-model-scholar. In the memoir, *Anais Nin: The Last Days* (2011), a kaleidoscopic vista of Nin's creative-intellectual work, relationship with people and her last days with her lover and unsung caregiver, Rupert Pole unfold with such candour and vivid liveliness. Kraft, who was entrusted with the onus of telling Anais Nin's story by Nin

herself, is conscious of the embalming, immortalizing or damning power of narration and the accountability such a power demands from the narrator.

In his work, *The Wounded Story Teller*, Arthur Frank groups illness narratives to three categories thematically: (1) *restitution narratives* with a theme of 'health getting restored' or in other words, narratives about illness and returning to one's previous state of health; (2) *chaos narratives* wherein incidents of life are contingent beyond control (3) *quest narratives*, in which illness turns out to be spiritual journey in search of oneself and deeper aspects of existence (xiv). In the narratives under analysis in this study, one may see all these thematic categories spilling over to one another.

A writer of autobiographical accounts and memoir may go through several moments of indecision, emotional mayhem and ethical dilemma before taking a decision about venturing into the formidable task of life writing, Worrisome thoughts about the opinions that others may form of the self, some degree of self-doubt and a sense of guilt associated with openly speaking about the dear and near ones are lodged in most of the attempts for representing and interpreting the self. Such major hurdles could nip the desire to write about oneself in the bud or compel a person to keep one's writings inaccessible to others (perhaps a secret journal or diary). The question raised in Judith Butler's *Giving an Account of Oneself*, "Does the postulation of a subject who is not self-grounding, that is, whose conditions of emergence can never fully be accounted for, undermine the possibility of responsibility and, in particular, of giving an account of oneself?" (19), explains the ethical dilemma of life writing succinctly. While trying to make sense of the failure of the subject to be able to give an intelligible, logical and convincing account of oneself, Butler points out that the failure does not indicate the erasure of ethical responsibility of the subject in a postmodern narrative context. Reconstituting the 'narrative' self is always already intercepted and disrupted by the other. Since the self as well as the other are implanted in and grow out of social structures, we are in a position to conceptualize the conditions under which responsibility is possible and moral life is required.

In Butlerian sense, we may acknowledge that the subject is not the basis for ethics but rather a riddle that ethics has to figure out. Then it follows that the subject is relational, and language and writing are well beyond its powers. Owing to the exteriority of the subject/ self, there is an intrinsic opacity that forbids it from providing a full account of itself to the other, the addressee of the account. The self may also bring about an othering of itself through writing and become opaque to its own view. This opacity will pave the way for reconstituting our notions about the ethical viability of giving an account of the self and may lead us to new ways of looking at epistemic and linguistic violence, accountability, and limits of expression.

Butler reminds, "... the very terms by which we give an account, by which we make ourselves intelligible to ourselves and to others, are not of our making" (21). She also adds: "It is only in dispossession that I can and do give any account of myself" (37). Writing about the self, one's or another's, always comes with the burden of accountability and answerability, demanding honesty and courage on the one hand. On the other hand, it is not unusual for a narrator of life-writing to be troubled by limitations of what could be stated about oneself or another. There are more reasons - other than the lurking presence of one's own othered self or potential readers as others - for the decisions a narrator makes about what has to be spoken about, kept unrevealed or reinterpreted. The utterances of the self are tangential and extrinsic to the self.

In contemporary times, it is heartening as well as disconcerting to see that people with stigmatizing conditions or physical or psychological disadvantages have begun to write about themselves profusely or are being written about. My stance about such proliferation of life-writing is coloured with optimism and skepticism. I will attempt to explain the ambivalence of my feelings regarding a proliferation of life narratives about illness, 'disability' or 'deviation from the cultural norms'. Writing about oneself under such circumstances as illness, disability or injury can be an act of baring it all or exposing the self to the world with frankness, daring and total disregard for the consequences. In doing so, one can effectively question social prejudices and

anachronistic ideas which had been taken for granted without rethinking about them in the light of the present. This possibility of critiquing biases and prejudiced practices by evaluating their relevance in the present or assessing their incompatibility with contemporary life often remains an ideal. In our understanding and formulations about the self, the body, the being and illness, we should be willing to accept that there is very little that can be termed as 'timeless'; everything is contextual and in a state of flux. Many a time, instead of questioning stereotypes and preconceptions about gender, body, social roles and institutions, life writing seems to validate and play along the 'normative'.

While writing about the life of oneself and another, traps of glorification and heroization lurk along the paths of the narrative construction of the self. Denise Riley points out:

... we need only glance around us to sense that the least ventures into any confessional – whether as deliberate autobiography or indirectly as poetry or history – produces obstinate knots of self-presentation. Any writer will inadvertently historicize herself in her work, however non-self-referential it aims to be. Describing myself, I set out the stall of my self, however reluctantly, as advertising. And if this is so, can speaking the self ever be managed without flattery or abnegation (*The Words of Selves* 28)

Narratives can be so full of oneself. Subconsciously, while engaged in an autobiographical exercise, one may have the potential responses and reactions of the readers in mind. This forewarning about how the readers would interpret the person's life depicted in the auto/biographical text may make the writer anxious about the possibility of a moral judgment and its effect on one's social image. Such trepidations not only influence the style but also the content of writing. Many calculations beyond additions and subtractions enter into the construction of the self in an autobiographical text. While producing a text by authoring it, one may become conscious about the text's reception not only in the author's life-time, but for several years, decades or even centuries after the author passes. In other words, apprehensions about the reception and interpretations of an auto/biographical

text, a living record, in and across time may in all probability influence the narration about the self and the events the self is part of.

A person who writes about another's life and experiences may feel paralyzed by ethical apprehensions. What has to be and ought not to be revealed as far as the life of another is concerned is difficult to determine. Rhetorical and aesthetic considerations apart, there is a troubling question about how much can another person be understood and unveiled by the life-writer. While some biographers are given into the temptation of sensationalizing, exaggerating or sometimes deliberately misrepresenting another's life for several reasons, some would play safe by turning into self-appointed censors and taking decisions about what is appropriate and non-offensive.

It is an impossible dream that representations of life should be true to facts and be exhaustive. There is no complete and correct auto/biography. Imagination and speculation cannot be walled out from the domain of life-writing. Nor can a person know every aspect of the self, one's or another's. Extra/ intra textual aspects of life writing compel one to ask several questions about an auto/biographical text and the political, aesthetic and ethical process of its production and reception. When it comes to life writing, simple questions about what (the focus and content of the auto/biographical text), why (purpose of writing about oneself or another), how (the modes of assimilation, selection, omission and arrangement of details) and when (what phase of one's or another's life is being written about and also the importance of timing the writing and publication of the auto/biographical text) cannot be answered easily. The intention of the life writer and the methods for interpreting and representing one's or another's life that a writer may resort to are not available to us. That is to suggest that one who attempts life writing or analysis of life-writing steps into a tricky, shifting and undeterminable terrain full of riddles and pitfalls.

I look at cancer narratives through three lenses focused at the ailing corporeal self: writing the life, writing to live or to keep oneself/ another alive and writing to life or writing as a means

to communicate with the living beings around with a hope to facilitate collective awareness and action. The study will analyze the aesthetic and ethical aspects of that particular trope of life writing informed by the experience of illness.

Writing Self, Writing the Self and the Subject of Writing

The study captures various levels of narrative engagements with a sick body, one's own or another's, which is perceived to be on the path to cure or at the threshold of death. The sick body, which could be weak, disfigured, devastated, damaged, non-functional, disabled, in pain or at the doorstep of death is not a simple and easily interpretable entity. It has to be understood to the minutiae of its cells and in the variety and vastness of its contexts. The ailing corporeal self is entangled in several strands of affective forces so much so that writing can aid in much needed release of emotions. Autobiography and biography are to be looked at as forms of life writing demanding different ethical standards. Writing about oneself and one's illness can be a mechanism facilitating the comprehension of an acutely trying experience of the self. It may be a strategy for consoling the self and protecting it as narration helps many in exorcising or pacifying the demons of awful emotions. Writing may be of use in coming to terms with illnesses and mortality of one's own or another's. A narrative exercise can act as a step taken in the direction of healing. Even if the narrator musters courage to speak the truth of the self despite the powers that be, writing is regulated by rhetorical tropes and societal concerns. Integrity, accuracy, appropriateness, diplomacy, political correctness and honesty do not coexist comfortably with each other.

Writing about oneself is not a straightforward and uncomplicated act of telling the truth about oneself despite various levels of controls and regulations that the writing subject experiences. The person writing the autobiography or recording a phase of one's life such as illness is not free from the constraints concerning how others can be represented in writings about the self. In one's own life story, 'oneself' is not the only character

though s/he may be the protagonist. In the case of the story of one's illness, members of the family, caregivers, healthcare professionals and many others who are part of such a phase in the narrator's life might get depicted. What and how much one may write about others who are characters in one's life story without hurting their autonomy and privacy is a pertinent problem. Telling the truth without tarnishing a person's social image, in many instances, is as good as creating a false portrait deliberately which has very little to do with the actual person being depicted. We cannot take lightly the question how the right to withhold consent to be made part of life writing as a character is to be secured. Can one's interests be protected while being turned into the subject of narration and how? The individuals appearing as characters in auto/biographical writing might feel wronged by the manner in which they are represented in the text. 'How and to what extent should *my* right and freedom to narrate or commoditize *my own* life by writing about it in a certain fashion be regulated by the right to privacy of others who figure in the narrative?' is a question that every life writer who portrays one's life may require to ask oneself. Consent and rights to privacy and autonomy are not limited to the narrow domain of legality. Defamation suits and compensations do very little to tackle such issues. In fact, more compassionate, sensitive and ethical reflections should come into play while representing others in one's life story or writing about another's life.

Writing about another is an ethically daunting task, especially when the subject of narration cannot take part in the process of narration, evaluate it, challenge it or change it. While one writes about a living sentient person, who can respond to the representations about oneself in the language of affirmation or defiance, the subject of narration is in a position of authority. In his *Vulnerable Subjects: Ethics and Life Writing*, G. Thomas Couser, making a case for 'Auto/Bio/ Ethics' or auto/biography's indispensable bioethical considerations, discusses how the subject of narration who cannot speak about oneself and for oneself is particularly vulnerable. Couser develops his argument around the text, *Elegy for Iris* (1999), a memoir by John Bayley about his life with Iris Murdoch, the famous British philosopher and novelist.

Iris Murdoch had a form of dementia towards the end of her life. Though Murdoch was not dead when this text was published, she was in no condition to speak for herself. She was quite secretive about her debilitating mental state and perhaps would not have liked to make it public through a published memoir, which was later adapted into a film. Murdoch was unable to challenge or validate the depiction of her ‘demented’ self and life. Nor could she have given or withdrawn permission to such a representation of herself by another in a commercial publication. In all probability, Murdoch was not even aware that Bayley is writing an account about a life that they have been living together. In the memoir, Bayley describes vividly about Murdoch’s incapacitating, dehumanizing dementia which reduced her to an ‘incompetent’ and ‘infantile’ being. Couser has his own apprehensions about taking great liberties with a vulnerable subject’s story.

In the “Preface” to *Vulnerable Subjects*, Couser points out that any representation in life writing can be *mimetic* (speaking about the subject) and *political* (speaking for the subject) and these categories are not mutually exclusive (ix). The narrator’s answerability is intensified when the subject of narration is unable to take part in the narration actively. The subject of narration who is the major part in the representation could be considered the protagonist of the story of life being told and all others and events revolve around this subject. If the subject of narration is incapacitated by illness, differently-abled or dead, its response to representations about and for itself would be nothing but silence. The self which is a ‘vulnerable’ subject of narration cannot speak about or speak for oneself. In other words, the ‘vulnerable’ subject of narration cannot question, dismiss or give another alternative account of the self. A narrator who tells the story of such a vulnerable subject should not be oblivious to the rights of the subject of narration and duties of oneself as the one who represents the life of the subject. Many a time, the narrator has access to and power over the life and details of life of the subject of narration and this power can easily be abused. For example, Bayley as a caregiver and partner living with Murdoch had a certain power over her. Couser is of the opinion regarding representing the vulnerable subjects that “The

closer the relationship between writer and subject and greater the vulnerability or dependency of the subject, the higher are the ethical stakes, and more urgent the need for ethical scrutiny” (*Vulnerable Subjects* xii). Writing about a vulnerable subject bears the threat of turning into an act of betrayal of trust by the narrator, if s/he ignores the right to autonomy and privacy of the person(s) being written about. Even if the subject of narration is dead, the apprehensions about autonomy and privacy are still vital. What if the subject of writing is a public figure whose right to privacy clashes with the readers’ right to know? How can a public figure defend one’s right to privacy against the self-serving and calculated interests of a narrator whose aim might be to turn a celebrity life to a saleable commodity by all means? What if the writer’s intention is to write some kind of a popular pejorative hate-narrative about someone who was an erstwhile celebrity and now vulnerable subject? Intentions can only be speculated about and speculations are seldom accurate.

Illness is such a powerful and intimate experience that writing about one’s or another’s illness demands ethical cautiousness and informed attention to privacy and autonomy. Writing about oneself and one’s sick body requires the willful overcoming of several kinds of inhibitions. Women’s body and her ailments are shrouded in mystery and silence. Cancer has an aura of mortal fear, stigma and pessimism surrounding it as it is popularly perceived as a death sentence. The treatment procedures of cancer are usually painful and packed with myriad prospects of misery and demeaning experiences. Going through cancer treatment may pose countless questions about quality of life and whether it is worthwhile to prolong one’s life by subjecting oneself to harrowing treatment procedures with an uncertain hope of arriving at remission. In short, going through the experience of illness makes one come face to face with and confront many unknown, unexpected and unpredictable aspects of oneself and situations of life. There are moments in illness when familiar and taken for granted aspects of the self systematically get annihilated, destabilized and reconstructed anew. It could be a baffling experience of ‘life in death and death in life’. Helen Cixous uses the metaphor of ‘bereavement’ to expound such experiences which she further explains this way:

Either there is bereavement between me, violently from the loss of a being who is a part of me – as if a piece of my body, of my house were ruined, collapsed. Or for example, the bereavement that the appearance of a grave illness in oneself must be. Everything that makes the course of life be interrupted....we are launched into a space-time whose coordinates are all different from those we have always been accustomed to. In addition these violent situations are always new. Always. At no moment can a previous bereavement serve as a model. (*Rootprints: Memory and Life Writing* 9)

With life derailing from the tracks of everyday familiarity, the self is shattered and reassembled, rather reconstituted. According to Helen Cixous, any kind of writing about oneself in such a scenario is prey to otherness (*alterite*). While writing about a self defamiliarized by redeployment of its various characteristics, we are:

Always in the process of betraying (ourselves), of leaving (ourselves).... We cut out a part of ourselves. We are torturous, impenetrable. We do the thing we just decided not to do. We are the place of a structural unfaithfulness. To write we must be faithful to this unfaithfulness. To write in voltes. In volts. (*Rootprints: Memory and Life Writing* 9)

It is not only that illness exiles us into an unfamiliar difficult terrain, but in our bodies, we feel foreign unto the self that has suddenly turned aggressive and hostile. Illness makes one experience a combat with an enemy from within. My enemy is my body, my corporeal self, I myself who was once so well loved by me has eventually turned into a traitor unto myself. Writing could be looked as a strategy to gain control over this seemingly losing battle.

As a reader of life writing also, one faces many ethical dilemmas. How does a reader interpret the negative views, indictments-, and judgments about the author's family members, colleagues, friends and healthcare professionals, institutions and administrators, which are not rare in life writing about illness? What does one make of such intense negativity and sometimes

even vicious name-calling? Is it a bold act of calling a spade a spade on the part of the narrator by laying bare the insensitivity, corruption, callousness and irresponsible attitudes of people, professions, institutions and healthcare industry? Is it a way of critiquing the systems and sites for taking care of the ill from the vantage point of personal first-hand experience with a hope of bringing in improvement? Is it a clever strategy for making things better for others by being brutally open about the shortcomings of healthcare that one has faced? Should one think, as a reader, that the writer of an illness-narrative must have devised certain plans for 'righting the wrongs by writing about the wrongs'? Is it the patient's way of negotiating with prejudices flourishing in familial and social spaces and in the profession of healthcare? Should a reader deal with the damning views of a 'wounded story teller' about people, particularly caregivers from family or professionals, institutions and healthcare systems as an arguably acrimonious and skewed perspective of someone going through a trying personal ordeal? Is it ethical to dismiss the views of someone who is ill about others and institutions as tinted by overwhelming self-absorption, self-pity, pessimism and anxieties that are perceived to be the inevitable trappings of illness?

Most cancer memoirs by women are written in retrospection, with a transparent intention to motivate patients and caregivers by sharing the memories of resistance to and victory over the fatal affliction. The narratives of struggle and triumph, meant to impart faith and hope, are available in plenty in the book market. Writers often take up issues such as the limitations of healthcare system and try to suggest alternatives. Some illness narratives also serve as self-help books discussing, with the authority of direct experience, symptoms, diagnosis, ways of coping with the illness and its treatment and possible side effects. Death is a subterranean presence in many narratives of illness. But several women who write on cancer tend to maintain a stubborn silence on the embodiment of illness and pain. The force of woman's bodily endurance of illness is stifled by a strict sense of privacy and secrecy.

More than the ethical dilemmas concerning the appropriateness of 'content' and mode of representation in cancer narratives, the

sheer reluctance to speak, write, reflect upon or engage with the experience of cancer, one of the most feared and stigmatized of diseases, bothers me. Why so much silence about women's cancers? Cancers affecting the female body parts are historically cloaked in inexpressibility. Siddhartha Mukherjee recounts the story of a Persian queen, Atossa,² recorded in Herodotus's *Histories*, to illustrate this culture of silence and concealment. Two thousand five hundred years ago, Queen Atossa, on noticing a bleeding lump on her breast, refused to access the easily available help of the illustrious Babylonian and Greek physicians. After spending a considerable time hiding herself from the world, she got the tumour excised by a slave. Atossa vanished from *Histories* - perhaps into a lonely, tortuous death. Reasons for this ritual of silence and secrecy around cancers of uterus, breast, ovary or cervix could be the indignity attributed to female body and its functioning. The prevalent concerns of modesty, tendency to privilege lone and quiet suffering over rage and tantrums, culturally constructed heroism of passive endurance and inability to give linguistic expression to intensely personal experiences may explain selective, inhibited speech and deliberate silence in the illness narratives by women. Another reason for silence is the helpless unspeakable nature of pain. David Morris, in *The Culture of Pain*, rightly observes that "Pain passes much of its time in utter inhuman silence, and writers who describe something so inherently resistant to language must inevitably shape and possibly falsify the experience they describe" (3). Elaine Scarry in her famous work, *The Body in Pain* discusses the curious connection between pain, initial silence and narration thus: "Physical pain has no voice, but when it at last finds a voice, it begins to tell a story" (3). It is pointless to ask, in illness narratives whether one constructs a story, recounts an experience or does both while in pain.

The narratives in this study capture the experience of cancer attacking or metastasizing on parts of female body such as colon, cervix, uterus, vagina, ovary, breasts and rectum - organs that are otherwise covered and covered up in embarrassment. These narratives are not merely triumphalist, pedagogic or inspirational; they explore the shadowy terrain of disease and its nuances

of embodiment. Narrators accomplish this by making their memories and desires heard over the din of cultural taboos and hushing shame associated with female physicality. Recording of experiences may be therapeutic for one who undergoes disfiguring curative protocols.

Narrative practices do give a sense of power and autonomy to the sick person who might otherwise feel ravaged and defeated. In his *The Wounded Story Teller*, Arthur Frank illustrates how illness is a mode of colonization in a modernist sense because the one who is ill submits one's body and stories/narratives about it to the care and control of experts. From a post-modernist perspective, the one who is ill reclaims the power or autonomy through narrative practices which are done with a unique sense of epistemic authority that comes through 'experiencing' illness so intimately, in the cells of one's body. That is to say that one who endures an illness also has a unique expertise to talk about it, which is not nullified by the expertise of the specialists who treat or cure the illness. Narrating is a way for salvaging one's life and stories from the wreckage of serious illness and injury (xvi).

In his *The Emperor of all the Maladies: A Biography of Cancer*, Siddhartha Mukherjee reports an incident in the life of Fanny Rosenow, a breast cancer survivor and cancer advocate, who called the *New York Times* in the early fifties to post an advertisement for a support group for women with breast cancer. The Editor rejected her request on the grounds that the *Times* could not publish words like 'breast' or 'cancer' and suggested that "You could say there will be a meeting about the diseases of the chest wall" (27). Betty Rollin remembers in *First You Cry-*, the time of her first diagnosis:

But it was 1975, when no one even said the word "cancer" (in obituaries the going phrase was, "he/she died after a long illness"); not too many people said the word "breast" and even fewer said the two words together. For all I know, I was surrounded by one breasted women, but we did not talk to each other because we were all hiding. (x)

While analyzing the narrative account of one's experience within the condition of illness, one must realize that illness is an

intense, invasive bodily experience that has cultural ramifications as well as personal connotations. Illness reconstitutes the narrating subject and shapes the patterns of self-understanding, expressions and silence. It is not really the ethics of truth in representing oneself that I am looking at; rather questions of agency and subject formation are the concerns of this study. Judith Butler affirms that any attempt to give an account of oneself necessarily involves the effort to make the narrator recognizable and understandable. The narrator in the text is made substitutable in order to be recognizable. In other words, "The narrative authority of the 'I' must give way to the perspective and temporality of a set of norms that concerns the singularity of my story" (*Giving an Account of Oneself* 37). The account of oneself is given for and to someone else and the "I" gets displaced. The experiential domain of the body is not fully narratable because of strategic selection and omission of memory. Butler states: "To be a body is, in some sense, to be deprived of having a full recollection of one's life. There is a history to my body of which I can have no recollection" (Ibid. 38). However non-memorizable or non-narrativizable the experiences of the body and the "I" emerging through such encounters with the 'other' be, narrative practices, to me, are a potential assertion of women's agency. It is not through the lens of legitimacy that I examine these illness narratives. This study also analyzes the role of women's body and its disfigurement in fleshing out her thoughts, illustrating how the removal of organs that have aesthetic, sexual or reproductive functions/connotations embodies her narrative persona and the physical and psychological shades of trauma.

Disease resists literalness and one often resorts to metaphors in its expression. Metaphors such as silent killer, crushing rock, doppelganger, hairball, spider, cockroach, crab, diabolic pregnancy and embryo of death are constructed around cancers. In *Illness as Metaphor*, Susan Sontag's caution against the use of illness as metaphor and taking asylum in metaphoric thinking points an accusing finger at the strategies of stigmatization, denial and myth-construction around illness. In her opinion, "Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. First,

the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor” (58). Metaphors of cancer have percolated into our thinking, expressions and culture as signifying the repression of passions and giving in to inhibitions. The belief that cancer originates from suppressed emotions, which later get expressed as malignant growths, is an example of a myth constructed about the disease. Metaphoric thinking may place the blame on the patient. Psychosomatic theories tend to depict cancer as an emotional failure. Sontag expresses the hope that as we become better informed about the etiology and treatment of cancer, its metaphorical system will die on the vine. On the other hand, metaphoric thinking, imagination and creative expression may lead to finding a new significance in life on the verge of death. Illness narrators cannot often bear the burden and banality of literalness; so the writer seeks help from metaphors without which thinking about illness becomes intensely distressing. Metaphors can be painful; they can also have a potential for healing. Language deserts the one who attempts to speak of the pain of the body. According to Elaine Scarry’s argument in *The Body in Pain*, “Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language” (5). That is one reason why the narrator of illness finds a safe haven in imagery and metaphors. Metaphors simultaneously mask and reveal the starkness of lived experience. It feels very convenient to speak indirectly and impersonally on illness: doctors prefer the term ‘malignancy’ to cancer; plenty of ‘ctomy’ words alleviate the linguistic fierceness of ‘cutting off’. Cutting off the breast sounds more gruesome than mastectomy. Hysterectomy does not convey the terror of cutting off and taking out the uterus.

In *Illness as Metaphor*, Susan Sontag makes a significant observation about the intimate physicality of cancer, “Cancer, as a disease that can strike anywhere, is a disease of the body. Far from revealing anything spiritual, it reveals that the body is, all too woefully, just the body” (18). In *The Invading Body*, Einat Avrahami draws our attention to the inevitable incomprehensibility of experiences of the body, “the persistent

reality of the writer's embodied knowledge continues to elude both our innate need for clarity and the integrative cultural patterns we recruit as a way of representing and conceptualizing it" (96). The inability to penetrate into one's own or another's physical plane of experience ushers the narrator and reader into a shadowy, twilight zone of partial comprehension and muted narration. Narrative practice is a discontinuous and inconclusive terrain where the polysemic nature of language, silence and prevalent cultural constructs tease us out of certainties, making us confront the limits of perception. In her Memoir about ovarian cancer titled, *No Time to Die* Liz Tilberis makes an observation about the symbolic intertextuality of cancer experience and narrative practices: "Any story about cancer is a palimpsest, written over many times, with the remnants of earlier stories imperfectly erased" (261).

Audre Lorde does not hide behind silence or soothing metaphors in her cancer narrative. While she penned her *Cancer Journals*, Lorde acknowledges the significance of naming the self in order to assert its multilayered identity with a political intent. As a feminist, she was aware of the white social and epistemological dominance in the feminist movement of her times and strived to make the black women visible and heard. She refers to herself repeatedly as a black lesbian feminist poet activist mother with breast cancer by way of making a statement about her concerns and never ending struggles for the rights of many women like her. Lorde integrates a fearsome, painful and life-threatening crisis as cancer into her identity. A chapter in her *Cancer Journals* is significantly titled "Breast Cancer: A Black Lesbian Feminist Experience" wherein she indirectly asks everyone to take part in her excruciating experience of living with cancer without suggesting that her experiences are unique or universalizable. Oppression, for a person living in America of Audre Lorde's time, was not limited to gender. During her life and illness, Lorde could garner insights into oppression based on race and sexual preferences. She believed in communicating the most private experiences to others rather than sheltering oneself in the comfort of numbness and cowardice. As someone who had absolute faith in the power of the collective, she has in mind as her

addressees an imaginary group of readers, especially women who, she hopes, can relate to her experiences and share a similar sort of anger at injustice. She was reaching out to other companionable women who had the verve and readiness to work hard to make things better for oneself and others. Narrative practices done in this vein may facilitate the coming together of people with similar concerns and interests through the act of writing, reading and interpreting one another. This in turn may create a sense of camaraderie and empathy among those who undergo similar ordeals in life.

The *Journal* takes us through the experiences of Lorde starting from the recovery room after a radical mastectomy where she is alone for a long time with her fear, severe pain, thoughts about mortality and anxieties about her unfinished life's work. During such an hour of crisis as advanced breast cancer, Lorde desperately looked around for literary models she can rely on, and experiential documents that would help her as guides for gaining perspectives over her illness. She says that if there had been texts – autobiographical works, poems or essays – in which she could read about other women's journeys of illness and pain, she would not have felt so lonely and clueless. She is painfully aware that many women, especially black women, die of cancer day by day; but very few take the trouble to share their experiences as a way of healing the self and for the benefit of others who feel trapped in the desolate confinement of illness, pain and fear of mortality. Lorde was troubled by the thought of her cancer spreading all over her body and even more disturbed by the spreading apathy among women. Women's culturally imposed reluctance to speak out openly about their personal experiences of pain, illness, violence and the like shuts each one in the shell of solitary suffering which turns them weaker and more vulnerable. Women are also made to shut up, deprived of the right to speak about and for themselves. Giving access to others into one's life-world is an important strategy for forming a support network of women for women. As women share their experiences and do focused collective work for prevention of the injustice that they suffer in their everyday lives, they come out of isolated and inexpressible distress, find their voices and discover the strength

of cooperation which would ultimately make things happen for their benefit and betterment.

In *Love's Work: A Reckoning with Life*, Gillian Rose shares what she has gone through in suffering from ovarian cancer and witnessing a close friend's death from HIV/ AIDS. Love's work for the author is a miracle, a message and an annunciation, which is full of ancient wisdom and newness of perception. It cannot be disconnected from one's being and existence. Her text touches upon bodies that are wasted and minds which are at work, churning out stories full of love and passion for life. When illness ravages the self and death is round the corner, the author is lost to deep ruminations on beauty, friendship, love and life's work in general. For her, love and life are inseparable. In the text, she uses terms like 'life affair' and 'love's work' to suggest mysterious connections and possibilities between living, loving and work full of vitality and passion.

Rose illustrates the problems of unexamined suffering by narrating how her mother, hailing from a Jewish family that had lost many of its members to the brutal violence of the Nazi period, lived in a state of denial about holocaust. It was perhaps a strategy invented to deal with the survivor's guilt. The mother may have experienced immense trauma as a result of being unable to face her agony; on failing to stare it in the eye. The unwillingness to enter the hell of one's trauma pushes a person down to an even more depressing hell escaping from which is not easily possible. Only by living in hell can a human being seek redemptions in the form of self-respect, contentment and integrity. The unexamined life is perpetual despair; an inexorable hell fiercer than suffering.

The epigraph of her text gives a powerful message: "Keep your mind in hell, and despair not." The philosopher-sociologist in Rose encounters the deeper terrors of the soul which are more potent than the fear of annihilation. For this encounter, Rose is equipped with wisdom and hope gained from suffering. She repeatedly suggests such encounters give meaning and purpose to human existence, a meaning that emerges partly from a continuing interaction between the past and the present which knows no cessation. One also engages with collective memories

and shared experience of pain and suffering, in her case Auschwitz, to connect to oneself and to others.

During the days of illness, certain decisions she had taken earlier appear bathed in rich symbolic significance. Incidentally, abandoning her biological father's surname, 'Stone', Gillian accepts the stepfather's last name 'Rose', which metaphorically indicates the shift in her epistemological pursuits also. She leaves stony silence, dry scholarship or an arid, rocky epistemic desert to explore landscape of poetry, dappled terrain of written word or gardens of life and beauty. It was a pilgrimage of wisdom from the 'Rock of Zion' to the 'Romance of the Rose' in which she meets power, grace, love and tenderness. But in her illness, she also realizes that rocks and roses coexist as pain and pleasure. Without suffering, life is empty. Without pain, life has no substance. It is by facing and facing up to suffering and coming to terms with it that one comes out of the hell of despair. Rose affirms:

The only paradises cannot be those that are lost, but those that are unlocked as a result of coercion, reluctance, cajolery and humiliation, their thresholds crossed without calm prescience, or any preliminary perspicacity. (*Love's Work* 40)

Before her health deteriorated, Rose had started working on *Paradiso*, a text that expands the major concerns of *Love's Work*. The text could not be completed before her death and it remains in fragments. The text was published as vignettes and pieces of poetic wisdom. *Paradiso* is about escaping the hell of despair, flying away spreading the wings of memories – memories and lived realities of love, work and companionship - in search of a paradise of self-discovery and fulfillment. In this text also, Rose emphasizes how important it is to venture into the depths of suffering to discover the tunnel leading to light and hope. Running away from suffering is fleeing from paradise. Rose is not referring to a simplistic notion of redemption through suffering. Escapism and denial on being confronted by suffering, which she calls 'unexamined suffering' can prove more agonizing than addressing one's suffering through contemplative, narrative and

other kinds of creative acts. These acts are ultimately love's work. For Rose, writing is not an end in itself. There are ways in which writing is transformed into love's work:

However satisfying writing is – that mix of discipline and miracle, which leaves you in control, even when what appears on the page has emerged from regions beyond your control – it is a very poor substitute indeed for the joy and the agony of loving. Of there being someone who loves and desires you, and he glories in his love and desire, and you glory in his every-strange being, which comes up against you, and disappears, again and again, surprising you with difficulties and with bounty. To those this is the greatest loss, a loss for which there is no consolation. There can only be that twin passion – the passion of faith. (*Love's Work* 58-59)

Moving on from her philosophy of suffering that enriches *Love's Work*, which she repeatedly sums up as 'keep your mind in hell and despair not', Gillian Rose takes us along on a tour of the hell of terminal illness to finally arrive at an affirmation of paradise. It is in the quiet joy of recollections, living, toils of life, affections, passions and other ties that one locates the paradise.

Memoir of a Debulked Woman: Enduring Ovarian Cancer by the feminist theorist Susan Gubar is an attempt to explain to herself and the world the experience of Stage III ovarian cancer and its somewhat dehumanizing treatment procedures. Through a devastatingly frank and vivid account of her cancer and its treatment, Gubar presents as subtext, a scathing assessment of the inefficient methods of diagnosis, treatment and management of ovarian cancer. Susan Gubar looks at the inhibitions of women about representing the sheer physicality of experience during illness. The body of women and her sexuality are often stigmatized and for this reason, women feel indisposed to express and represent themselves. Representing is not only about being part of a narrative; it is a political act demanding the right to be treated as an individual in whom is vested the power to take decisions about oneself and one's life.

In Gubar's case, writing the *Memoir* was done simultaneously with painful surgery, chemotherapy, ileostomy, and infections she suffered during the treatment for cancer. Unlike the popular, feel-good, upbeat illness narratives that are flooding the western book market, Gubar's book does not celebrate the virtues of reticent suffering or unfailing hope. Her account of gross disfigurement and unbearable pain resulting from surgery and chemotherapy which are worse than the symptoms of cancer may even discourage others from opting for standard treatment procedures. She does not hesitate to portray her fear, anxieties, sorrow and despair and admits that her response to cancer was by no means heroic or exceptional. But writing was a way to rage against and reconcile with illness.

Susan Gubar in her *Memoir* does not conceal herself in premeditated silence or resort to discreet metaphors. She uses 'debulking' as a metaphor to enrich the narrative and substantiate her critique against 'standard treatment procedures'. Bulk is fullness, life-force, and presence; 'debulked' is being scooped out, drained off the life-force and energy, signifying void as an ugly reality. Reading and writing helped Gubar feel less forlorn in the ruminations on her impending death – a state that she shared with many unknown far off women. Moreover, against the emptiness of debulking, she could sense the fullness and fulfillment one experiences while writing. Gubar felt that though all of us are in remission from the inevitable mortality, it always feels precipitous to arrive at the terminal. Cancer gives the experience of a posthumous existence. However, being at the threshold of death elicits different responses from people. Gubar's acceptance of impending death is full of grace: "Cancer and its treatments teach us...that life without the finitude of death – the inconceivable finality of one's own death would be intolerable" (30). Death is an ever present preoccupation in the life of someone suffering from a terminal illness – a door ever ajar. It speaks a language accessible only through a complete involvement in the process of dying, waiting for or fearing death. Gubar sheds light on the narrative inquiries into death and death's simultaneously severe and soothing pedagogy. She incorporates in the narrative the tacit possibility of a recurrence of her deadly illness to reaffirm her inability to escape from death or

its thoughts. Paradoxically, Gubar talks about an initial euphoric sense of liberation that she experienced after coming to know of her diagnosis. She has been witnessing the slow degeneration of her elderly demented mother and had developed an extreme fear for incapacitating old age. Gubar finds comfort in the thought that since she has led a full life, raised a family and achieved professional success, it would not be such a terrible time to die. She does not lament, “why me?” and states that should it not be, considering her family history of cancer, “Why not me?”

Gubar’s *Memoir* explores the pain and trauma on her body’s treachery and the dreadful procedures of oncology. She unequivocally represents the emotions of a ‘debulked woman’ with a scholarly awareness of the historical nuances of women’s body – in pain, disfigured, or under the threat of death. The memoir proclaims that a loving commitment to several aspects of existence – one’s life, presence of dear ones, commitment to literature and scholarship – reinforces sensitivity, compassion and most importantly one’s will to survive meaningfully. The narration in the *Memoir of a Debulked Woman* may seem slightly disintegrated and Gubar tends to repeat certain ideas for emphasis (especially her critique of the medical establishment and its role in the stigmatization of women’s bodies). The text provides information on cancer solicitously and rather uninhibitedly. It is poignant without being melodramatic. Towards the end of the book, we see Gubar prepare for an abdominal surgery following a recurrence of cancer.

Simultaneously a montage and palimpsest incorporating the life-worlds fleshing out around the corporeal experiences: that is how moments of illness, violence and environmental devastation *In the Body of the World* are remembered and narrated by Eve Ensler. Ensler observes: “This book is like a CAT scan – a roving examination – capturing images, experiences, ideas and memories, all of which began in my body” (9). Ensler’s musings on illness form a web of associations, narrative threads emanating from her body and spreading over the world, refusing to take a predictable path of discussing diagnosis, hospital, treatment, and cure/ healing, remission or death usually followed by the stories of cancer. Ruminating on the horrors of living with an illness

that steals beauty from life and translating such a life into a work of art is what Ensler does in this text.

Ensler's recollections of her cancer are intertwined with her memories of being raped by her father and her experiences as an activist helping women who are being "molested in their beds, flogged in their burquas, acid-burned in their kitchens, left for dead in parking lots" (4). After visiting the refugee camps and rescue shelters at Jalalabad, Sarajevo, Alabama, Port-au-Prince, Peshawar and Pristina, she witnesses the end of the body, humanity and the world in Congo. In her own words, "Femicide, the systematic rape, and destruction of women and girls, was being employed as a military/corporate tactic to secure minerals" (5) that are used in our fancy gadgets.

Cancer connected Ensler to her body to such an extent that she becomes her body; Congo, where she worked for the welfare of women who were subjected to extreme forms of violence, landed her in the body of the world. Destruction of the uterus and vagina by cancer and its invasive treatment that the author suffers; wounding, burning, whipping, raping and deliberate damaging of female bodies that she witnesses as a social activist working with women; mining, deforestation, oil spills, disruption of food chains that earth endures on her flesh: such scenarios of gradual and pitiless ruining leading to extinction are interconnected in the text through the metaphor of an unhooded, unloved, subjugated state of alienation.

There are other kinds of auto/biographical accounts of cancer in which one's experience of disease becomes a pretext and context for talking about concerns of great import related to illness in general. Susan Sontag's *Illness as Metaphor* written in 1978 is a path breaking analysis of the semantic and figurative constructions around illness. After having experienced cancer and its treatment, Sontag realized how metaphors and myths surrounding the illness create such an aura of stigma and mystery around it that people feel hesitant to speak about it or seek medical care. Metaphorical thinking happens when the illness is supposedly intriguing and formidable. That's the reason why there are so many metaphors about tuberculosis, cancer and AIDS.

But metaphors do very little to explain the enigma that is illness or lessen the suffering of patients. In her attempts to demystify consumption, cancer and AIDS, Sontag wants to emphasize that these are just diseases, which can be cured or managed if proper treatment is given. An illness is not a curse or punishment and there is nothing to be embarrassed about it.

Sontag argues in favour of resisting the impulse to treat illness as metaphor or to generate metaphors out of illness. She starts *Illness as Metaphor* with this statement: “The most truthful way of regarding illness - and the healthiest way of being ill - is one most purified of, most resistant to, metaphoric thinking”(1). Diseases take turns to enter into the snare of metaphorical thinking. Sontag points out that tuberculosis was deeply entrenched in metaphorical figurations and expressions. It was a disease of passion, excesses, burning and consumption. As and when prevention and cure for TB were discovered, the perplexing aura around it began to fade away. TB stopped fuelling metaphorical thinking as it ceased to be a romanticized enigma. It was just a disease caused by bacteria. Then it was cancer’s turn to fan the flames of metaphorical thinking. It is popularly perceived as a disease of inhibition or repressed passion and unexpressed emotion which accumulate and get hardened into malignant growths. The myth construction and metaphORIZATION around illness will stop only if the illness is properly understood and controlled in terms of prevention and cure. *Illness as Metaphor* points out the potential of illness metaphors to put blame on the patient. For example, the myths such as ‘cancer personality’ can lead to patient blaming. The war metaphor surrounding illness can suggest that a patient who was *defeated* by illness did not *fight* her or his *battle* well enough. If you call poverty as the cancer of current economy, you stigmatize the illness and also the ill to some extent. That is what metaphorical thinking does to illness: turning each illness into a lurid and fearsome myth. Sontag is silent and oblivious to the healing powers of metaphORIZATION.

Bearing Witness: Life, Disease and Death

After these narratives about illness which are autobiographical, I would now analyze a few texts that deal with the life, disease

and death of another. *A Very Easy Death*, Simone de Beauvoir's memoir about the last few weeks of her mother who died of cancer gives a vivid picture of her family helplessly going through the trauma of a dear one's suffering. Keeping the devastating moments of being a caregiver to her ailing mother as the background, Beauvoir touches upon peripheral issues of tension and negotiation in relationships while a crisis gapes you in the eye. She uses the memoir for talking about isolation and vulnerability of old age and how powerless one feels while confronted by a fatal illness. In her story of love, illness, death, grief and healing, Beauvoir throws open a plethora of issues for reflection with raw honesty. This book published in 1964 is also a document laying bare the shortcomings of medical practices, cancer treatment and palliative care in the 20th century.

Many a time, cancer comes in disguise and reveals itself only when it is too late. Beauvoir's narration maintains a somewhat emotionally involved, yet analytical tone throughout as she narrates how her family was pushed into the world of cancer after the unexpected cancer diagnosis of her mother in 1963. The mother who was seventy seven had apparently innocuous symptoms as weakness, abdominal pain and arthritis-related issues which one may dismiss as unavoidable companions of old age. After falling unconscious one day, the mother was admitted to the hospital with a minor fracture. Maman started experiencing agonizing gastrointestinal problems and the doctor suggested further investigations. She was diagnosed with advanced sarcoma of the intestine, a state and stage of cancer where very little can be done in order to possibly save the life of the patient. Even after a laparotomy and tumour surgery, the cancer advanced in leaps and bounds. Maman's condition worsened to such a terrible state as incapacitating complications followed. She survived for a few weeks after the surgery and till her extremely agonizing death, she was kept ignorant of her diagnosis. Beauvoir wrote an account of the brief period of her mother's illness and death in 1964.

This text is an insightful account of what illness and old-age do to women. The fact that both the diagnosis and the prognosis

of her own illness were not disclosed to the mother seems to be unethical and unimaginable according to today's standards. At the same time, we are told that the ailing mother basked in vacuous and fake optimism and died somewhat peacefully despite her physical discomfort. The text provides a vivid picture of the ordeal of the caregivers: their shocks, frustrations, helplessness, indecision, despair and sense of guilt.

The reasons for taking a decision to write about the sickness of another could be so varied. The last days of her mother filled Simone De Beauvoir with an abundant wealth of experience and insight. She thought recording those moments would be a duty unto oneself, to her mother and a responsibility to many who go through such harrowing phases in their lives. Writing becomes an act of expressing love that had long been forgotten, but has all on a sudden welled up in one's deeper self:

I had grown very fond of this dying woman. As we talked in the half darkness I assuaged an old unhappiness; I was renewing the dialogue that had been broken off during my adolescence and that our differences and our likenesses had never allowed us to take up again. And the early tenderness that I thought dead for ever came to life again, since it had become possible for it to slip into simple words and actions (76).

Two biographical accounts - *Sempre Susan* by Sigrid Nunez and *Swimming in a Sea of Death: A Son's Memoir* by David Rieff - portray the cult figure of Susan Sontag undergoing cancer treatment and raging against mortality. *Sempre Susan* is about a few significant years in the life of Susan Sontag. Sontag after being diagnosed with Stage IV cancer was hoping against hope for a few more years of productive work. Nunez visited Sontag while she was recovering from the cancer surgery and looking for someone to answer her mail. Nunez got the job and eventually began to date David Rieff, Susan Sontag's son. Sontag's relationship with Annie Leibovitz who was her partner of several years was on the rocks, as a result of which she felt insecure and abandoned. The fear of solitary suffering, being uncared for and dying alone haunted Sontag at this phase of her life. That was the reason why

David Rieff and Nunez started sharing the flat with her. *Sempre Susan* is an account of a quietly turbulent time in the life of Sontag, Rieff and Nunez. In a *Paris Review* interview, Nunez talks about how she put to rest her concerns about Susan Sontag's privacy: "...she was in fact the least private person I've ever known. She told everyone everything: the most intimate details about her life, all about her personal history, the people she knew, famous or unfamous, what she thought of everyone and everything—she had no use for secrecy or even for discretion."³ The ambivalence and uncertainty of this narrative makes it very powerful. In the light of Nunez's conflicting feelings about Sontag, we observe Sontag, a bundle of irreconcilable contradictions, more closely.

David Rieff's memoir is a tribute to his mother and also an attempt to interpret her complex life and death. The son is both a caregiver to Susan Sontag and a witness to her nine months long suffering. The zest and eagerness for life that Susan Sontag carried to her grave and her insistence to die a dignified death are narrated poignantly. A confrontation with and the aftermath of death are major thematic concerns of Rieff's memoir as he portrays his own guilt-ridden state full of self-questioning and a terrible feeling that he has not been able to do enough for his mother. David Rieff's memoir is about himself as it is about his mother.

Rieff was in the middle of an important professional assignment when Susan Sontag mentioned about the result of her blood not being good. She was diagnosed with myelodysplastic syndrome (MDS) and she died of myeloid leukemia a few months after that. Sontag survived advanced breast cancer in 1975 and uterine cancer in 1998. On being told about her third cancer diagnosis in March 2004, Sontag perhaps had a strong hope that she would sail through the turbulent ocean of illness to the shore of health this time as well. But in nine months, by the end of the year, Sontag was gone. She would demand that she should be told the truth about her illness which of course was not reassuring. She was determined to survive because she had many ideas waiting to be written as books. Sontag also wanted to publish more novels.

Illness may rob oneself of dignity and fortitude. Sontag subjected herself to terribly dehumanizing procedures of cancer treatment with full faith in the possibility of a prolonged remission, if not a complete cure. The thought that she might soon die would have certainly unsettled her. Rieff feels that the calm and seemingly brave suffering of Sontag and her relentless hope were in fact loud symptoms of her almost insane denial.

Susan Sontag looked at illness as a pedagogic opportunity and also an occasion to prove herself. After receiving the diagnosis, while being driven back home, Sontag utters, "Wow," looking out of the car window. She would read carefully and underline relevant points in the pamphlet circulated by the Leukemia and Lymphoma Society. Rieff stopped taking notes about his mother's condition when he sensed the beginning of an end and deterioration of her physical and psychological being. Sontag believed in her exceptionality and was confident that she was different from the other women of her time. She was willed to be unique and peerless in everything that she did. She might have even felt too special to die, according to Rieff. But cancer breaks down that illusion and she stops feeling special or exceptional. Illness in a way reduced her to yet another person suffering from a life-threatening disease and she realizes that death is not going to give her a kinder treatment by sparing her. She cannot bounce back once again to her life and life's work.

After her earlier encounters with cancer and recovery, Sontag was excited about her near-death experiences. Having reached so close to death and returned to life, she discovered a sense of liberation and fierce courage. She was pleased by the ways in which these new discoveries had enriched her work. But in her third and last encounter with cancer at the age of 71, Sontag had to accept her unavoidable death and could not grab yet another opportunity for new insights into life. Disease and near-death experiences were not themes to write about anymore.

Rieff had a dreadful time as a caregiver because he knew how much Sontag yearned to live and continue her life's work when there was no scope for hope. He could not bring himself to utter those hollow words of comfort and assurance that Sontag wanted to hear from him every moment. The extreme

measures to which Sontag subjected her body with the hope of curing her cancer were useless and Rieff, who knew the futility of further treatment, had to be a helpless onlooker and reluctant accomplice. Sontag yearned for frequent verbal affirmation from her son that she would survive. She also craved for a fantasy of her own invincibility and immortality. Rieff could provide neither an assurance of victory over death nor a promise of immortality. His inability to tell comforting lies set him on a guilt trip. During her breast cancer experience, Susan Sontag wrote in her Journal: "In the valley of sorrow, spread your wings." Rieff confesses in his narrative that this was not the way she died.

Barbara Kraft's work *Anais Nin: The Last Days - A Memoir* is a biography in which the narrator is an important character. It is a story about Nin, it is partly a story about Kraft. It is about how crisis cements relationships and ties people together in unforeseen ways. Trusting someone with one's own story is a rare thing to do. That is what Nin did. The woman who had a larger than life aura about her suddenly came in touch with a meager and defenseless corporeal self. A self that is mortal and packed with pain and vulnerabilities. Nin's vaginal cancer and Kraft's painful divorce create a situation of interdependence between these two women and they could find solace in each other's company and narration. Nin was dying and her body getting gradually destroyed by cancer treatment. Yet she showed interest in Kraft's decisions about her life and dream-career as a writer. Nin grew fond of Kraft because the famous author could see a glimpse of herself in the young and aspiring writer. Despite her serious condition, Nin wanted to help Kraft by offering support and advice from time to time as a veteran successful author. Nin requested Kraft: "I can't tell the world about my illness, Barbara, but you can, and I want the world to know. I want you to write about this." (2)

In December 1974, Anais Nin was hospitalized with advanced cancer and had to undergo surgery. She had to revisit the hospital in the coming years for more surgeries, chemotherapy and radiation. Nin lost most of her beautiful golden hair and was attached to bags and tubes all the time so that fluids from her body ravaged by surgery can drain out. During this period, Barbara Kraft used to visit Nin to listen to and record Nin's story

of life, love and passion. Though cancer 'felled her at the very apex of her long awaited literary success' Anais Nin fought 'a heroic battle against cancer' (5). Nin's passion for her life never abated. Yet during a prolonged phase of illness preceding her death in 1977, Nin realized that death is a great leveler and even with the magic in her words, she cannot wish it away. There was a deep dignity in Nin's acceptance of death. The narrative is also about Nin's lover Rupert Pole whose affection and dedication as a caregiver was remarkable. Pole shielded Nin from the indignity and humiliation of disease and tried to ease her pain and suffering with his kind words and deeds of loving-care.

There are no definite and singular answers to the questions I had been asking myself and others during this study: "What is there in illness that prompts some people to reflect on the self, life and record one's experiences?" "While many become more silent and withdrawn when illness strikes, why some others feel an urge to express themselves?" "What does life writing as illness narrative entail?" "Do people write with a purpose: to be remembered, to be instrumental in creating awareness and facilitating social change, or to be able to create yet another best-seller?" Writing is often an adventure of the self. It is both venturing into the self and setting out on a journey beyond the self. The self that writes with illness or death or both looking over its shoulder into the text is an image that is invoked in my mind when I think of narratives about cancer used in this study. Why one writes when an illness possesses the corporeal self as an uninvited and malevolent visitor fetches a variety of answers. Writing may banish the fiends of sorrow, pain and confusion. As discussed in this section of the study, a narration could be for explaining the self and its plight to oneself and to others. Illness may turn into a condition for bottomless self inquiry which wellness cannot bear to facilitate. Writing about one's or another's illness can be an act of love and memory, 'love's work' as Gillian Rose may call it. Narratives about illness can be a brave effort to speak truth to power by exposing the vices and flaws of the healthcare system.

The act of writing about illness has dimensions other than aesthetic. The ethics and politics of life writing based on illness demand a sensitive and perceptive understanding. The writing self

may go through a labyrinth of ethical dilemma before discovering one's voice for telling a tale of body and ailments. The ethical concerns of writing about one's or another's illness however remain unresolved because what is appropriate and permissible in the light of human beings' right to privacy and autonomy cannot be determined in a simplistic manner. Disease is ambivalent as it holds one back from and spurs one into writing. It is by no means easy to write with illness still on the body or in one's memory. Still people write, because writing is an act of affirming one's aliveness. It challenges annihilation and helps one get a sense of enduring vitality.

Cancer is not a death sentence. People survive, enjoy very long remissions and sometimes never does cancer relapse. Life during cancer treatment can possibly make one think that death would be preferable to a life of torment and suffering. But a post-treatment life which is symptom-free may make people partly forget the hardships of surgeries, chemo and radiation. Sometimes people live a life of extreme caution and care to prevent a recurrence. They might feel that their body has been damaged and immune system heavily compromised as a result of prolonged treatment. Everything about life may change: eating habits, attitude to others, work and relationships, equation with oneself and broadly one's philosophy of life. There are narratives coming out of a period of remission in which the experience of cancer is recollected and written about as self-therapy. Writing could be done consciously as an informative and comforting narrative practice which to the narrator is a responsibility to oneself and others. There is a refusal to forget suffering as the narrators keep revisiting its abysmal landscape in search of meaning. The narratives which I have used in this study have death as a lurking theme. To write is to distance oneself from death; in writing one takes a new birth and discerns a novel vitality in the dying body.

Writing to Keep Oneself Alive: Rediscovering Vitality on Facing Death

The autobiography that Gabriel Garcia Marquez wrote in Spanish in 2002, which was translated into English in 2004 had

the title *Living to Tell the Tale*. Marquez was living with cancer in remission while writing *Vivir para contarla*. The work was projected as the first book in a three volume autobiography. Marquez lived for over a decade after *Living to Tell the Tale* was published, but could not write the last two volumes of his autobiography. The title brings multiple likelihoods of significations. One meaning could be that a person lives so that the story of her or his life could be told. A person buying time before death to tell a story and hoping to keep death at bay is a moving image. The idea of telling a story to keep oneself alive is an old metaphor. That is how Scheherazade, the narrator in *Arabian Nights* managed to remain alive. Another meaning could be that it is through writing and artistic creation that one aspires for immortality. One's creations would survive the mortal body: be it a text or a painting or sculpture. So life narratives on illness may have an implicit desire for defying death through narrativizing life.

Cancers leave their own inscriptions - indelible surgery scars, disfigurements, amputation of body parts considered to be uniquely 'feminine' and unbearable pain - on the bodies of women. The changed body and changed self often take refuge in narrative practices for coming to terms with the difficult newness created by illness. The observation of David Morris in *Illness and Culture in Postmodern Age* sheds light on the overwhelming transformation brought about by illness:

Illness threatens to undo our sense of who we are. Its darkest power lies in showing us a picture of ourselves - false, damaged, unreliable, and inescapably mortal - that we desperately do not want to see. A serious and protracted illness constitutes an immersion in an alien reality where almost everything changes. (22)

Illness is sometimes an experience of undoing the self: shedding familiarity and ushering strangeness and disjuncture. One feels dead unto oneself by turning into an unrecognizable person. In appearance and character, one may become a shadow of the self that existed before illness, a spectral self. Writing on one's experience of illness is a survival mechanism adapted to counter this physical and psychological wreckage. Narrative

practices may help one make sense of an alien reality, enter into and comprehend it and reach a cathartic state in its tragic intensity. A writer, for many reasons, turns to a la Scheherazade as s/he narrativizes the trauma of illness. Writing about a painful and distressing ailment during its occurrence may vastly differ from the recollections of its agony after being able to distance oneself from it temporally and spatially.

For Audre Lorde who led a life of ideas, speech, writing and focused activism, cancer diagnosis was initially such a shock which paralyzed her with fear. She knew that the malignant tumour found on her breast has changed her life forever. She overcame the paralyzing fear and realized that despite impending mortality, there is a great deal that life can offer her. Also there is a lot which she can contribute to the causes close to her heart and the world at large despite her condition. She turned the fierce pedagogy of pain and fear to her advantage. In doing so, she had in mind her responsibility to her sisters: women who are united by the trials and tribulations of life.

Gillian Rose realizes the beauty and purpose of love and life by moving closer to death. When she reaches a philosophical understanding of her own ovarian cancer and copes with her friend's death, who passes away after many years of living with HIV/AIDS, Rose cannot stop marveling at the fullness of reinvigorating insight that only mortality can provide. Unfortunately, such an insight is not available to her surgeons, because of their inability to interpret death in a non-medical sense as a result of which they fail to understand life and perhaps even love. Life is inclusive of death. Without mortality, existence is devoid of meaningfulness and purpose. It is the *precariousness* of everything, risks involved in loving and living and pretty much in all aspects of human existence that makes philosophy and poetry possible. Cancer is that precariousness which Rose integrates into her being and existence following which profound reflections and expressions pour out of her being. She is convinced that enlivening mystery of existence percolates into our self and work through the conduits of precarious illness and impending death.

Illness and fear of death may make one feel powerless. In the moments of such abject powerlessness, we are at the mercy of

others. Rose sums up how relationships, life and power are so beautifully part of the web of writing as love's work:

In personal life, people have absolute power over each other, whereas in professional life, beyond the terms of the contract, people have authority, the power to make one another comply in ways which may be perceived as legitimate or illegitimate. In personal life, regardless of any covenant, one party may initiate a unilateral and fundamental change in terms of relating without renegotiating them, and further, refusing even to acknowledge the change. Imagine how a beloved child or dog would respond, if the Lover turned away. There is no democracy in any love relation: only mercy. To be at someone's mercy is dialectical damage: they may be merciful and they may be merciless. Yet each party, woman, man, the child in each, and their child, is absolute power as well as absolute vulnerability. You may be less powerful than the whole world, but you are always more powerful than yourself... *Love is the submission of power.* (*Love's Work* 54-55; emphasis added)

Gillian Rose treats writing as a sacred responsibility to live and the living that she fulfills while on her way out of life. On being challenged by death, she writes about her determination to continue love's work: "I will stay in the fray, in the revel of ideas and risk; learning, failing, wooing, grieving, trusting, working, reposing – in this sin of language and lips" (*Love's Work* 144). Work is not merely duty or a professional obligation for her. It is the path through which the purpose of life and love can be reached. It is one's responsiveness and responsibility to the self. She affirms: "The meaning of the work opens up the meaning of life. Psychic distress, with which we are so doggedly familiar is enlisted in the ineluctable paradox displayed in ever life of power and powerlessness, of appearing and remaining hidden" (*Paradiso* 32).

Reading and writing provided a much needed lifeline and strategies for coping with pain for Gubar. Reading cancer narratives, researching on artistic representations and literary expressions around cancer and synthesizing all these in her

mind during the treatment, she could bond her experiences with those of other women — hence ascertaining a kind of cohesion with fellow sufferers who were otherwise complete strangers. The women with whom she established these invisible links were fictive and real, from the past and the present. Gubar feels happy that her pursuit of knowledge has never been a solitary endeavour which cut her off from the rest of the world. Unlike the formidable scholar Professor Vivian Bearing, the protagonist of Margaret Edson's play titled *Wit*, who goes through the experience of terminal ovarian cancer all alone, Gubar does not feel forlorn. Her family, colleagues, students and friends give her much needed support during her predicament. Immersing her mind in literature, art and music soothes her further. In an interview, Gubar said, "Yes, I was reading and writing from the beginning, and until the present moment, because both reading and writing were and are a lifeline for me - a lifeline to other people and to understanding what I am in fact going through."⁴ Perusing the memoirs of other women, Gubar understood that they feel inhibited to talk about the degrading side effects of chemotherapy, changed appearance and concerns of sexual passion being drained off by illness.

During the treatment, Gubar realizes that cancer becomes her singular preoccupation that does not permit any distraction. The impulse not to surrender to inevitable death and concern for feelings of her family make her undergo a second cycle of treatment procedure. Processes meant to cure that appear to be physical torture involved in the treatment of ovarian cancer smothers her thoughts, memory, and feelings, reducing her cerebral faculties to a chemo-brain. Cancer treatment which offered neither cure nor healing convinced her that there are worse conditions than mortality. Gubar's scholarship in women's perception of their bodies and how those perceived bodies influenced the cultures they inhabited and constructed seeks an opportunity to expand its horizons during her illness. She has apprehensions whether her skeptical attitude towards the medical establishment, especially her mistrust of male physicians who consider female reproductive organs to be abnormal, impure and merely functional paved the way to cancer. Though she had some gynecological problems

years ago, Gubar refused to undergo radical hysterectomy, ignoring the advice of a male gynecologist. She observes in her *Memoir*: “My qualms about gynecological practices will probably result in my death. I squirm at the thought, consoling myself with the notion that feminist rhetoric today has become more nuanced than it once was and that writing about the disease will provide recompense for my earlier reticence” (56).

Eve Ensler points out in her *Memoir* that the greatest peril is not illness or violence, but being cut off from the flesh of life as illness and violence alienate one from life. It is the faculty of words as a narrator and the world demanding her active presence that redeem Ensler from the plight of being rendered obsolete and numb. Illness is about becoming “a stranger to myself and to the rhythms of the Earth” (1). Narration, an attempt to accomplish disorientation and harmony, is a life force and home-like space for revival and retribution comparable to the concept of the City of Joy (a sanctuary, place of safety and companionable empathy for the women of Congo who have suffered unspeakable violence). It is this dream of constructing the City of Joy that gives Eve Ensler a powerful motivation to be alive, besides writing and activism.

After being diagnosed with cancer that had invaded her body tormented by incestuous rape and abused by loveless sex, alcohol and drugs, her decision to go to Congo illustrates how she prioritized healing herself over finding a cure for the illness in the US. The cancer town may cure, but for healing she must travel to Congo which is a symbolic crossing of the river Uji (crossing over to a heightened state of consciousness according to one of the Buddhist traditions). Time spent with fellow sufferers and activists tie Ensler firmly to life. This connection is reinforced by the act of writing *In the Body of the World*. The cancer cells of violence are nurtured by passive indifference and silence: this suggestion resonating throughout the *Memoir* forces us to do an accusatory self-examination of our attitudes to the body – body of the self, of the other and of the world being assaulted and slaughtered moment by moment.

Ensler initially was in a mode of denial of the symptoms that rather openly warned about death, very similar to human beings’

blindness and deafness to nature's warning signs such as climate change, calamities, rising sea levels and the like foretelling the doom of the planet. Ensler connects this self-destructive denial to her habit of pretending to be asleep when her father raped her and her mother's willful neglect or pretended ignorance of the daughter's trauma. Denial arises in the absence of love, out of dissociation with life, and from a will to die. During the surgery for a possible cure, the cut starts at Ensler's belly button, symbolically indicating the slicing of the umbilicus, the first act of severance from the mother. Writing, performance, activism, love, communication, empathy, seeking solutions together and striving for collective good – acts that rage against insensitive aloofness and the dying of light – help one reconnect to oneself and the world. In the process of narration, the author looks at horror and tragedy in the eye, exposing herself to the memories of violence and trauma with a masochist zeal, reliving the moments of what she had witnessed and suffered. It is through the vulnerabilities and ugliness of the ailing body that Ensler finds her voice and strength, and the beauty of living despite the illness.

Writing to Others or Writing as a Form of Communicative Action

Rilke's ambivalent aphorism in *Duino Elegies*, "For beauty is nothing/ but the beginning of terror we can barely endure/ and we admire it so because it calmly disdains/ to destroy us. Every angel is terrible" (3) illustrates a philosophical-experiential impasse wherein the mind is in awe of a moment of discernment between beauty and terror. Such moments are not uncommon in the treatment of diseases popularly considered capricious and fatal. The treatment begins with beautiful promises of life, cure and healing; yet in powerless moments when one submits the body to the expertise of doctors, fear of death or of a survival worse than death may slowly overshadow the happy prospect of many more years to live. The treatment procedures of cancer often are more harrowing than the disease itself. Medical practitioners cannot always take into account the importance of healing or the quality of life since their primary concern is to save the patient's life. One invariably has several confrontations with the terrible

face of angels during presumably life-saving procedures. The side effects, scars and voids left on the body might stay on, giving a sense of ugliness despite the assurance of an extended life.

Cancer changes the body-self. Several feminist thinkers, especially Susan Bordo have cautioned women to seek freedom from the aspiration to conform to a culturally constructed (constricted?) ideal body image in order to please others. It is more liberating and empowering if women are comfortable with their own bodies and do not care about how they are gazed at. The culturally constricted ideal body image operates like an Iron Maiden that Naomi Wolf discusses in *The Beauty Myth*. Iron Maiden, a cold metallic instrument of torture shaped like the body of a perfect woman has spikes or saws fitted inside; a body shut within it would die bleeding in the suffocating darkness. Wolf illustrates, using the analogy of the Iron Maiden, how torturous it would be for a woman to confine herself within an overpowering and deeply penetrating cultural normativity enclosing her corporeal identity. This kind of cultural normativity targeting the body is a death sentence to all other aspects of women's identity, annihilating everything except a biologically/corporeally restricted selfhood. In other words, a woman's worth is reduced to a culturally prescribed norm of a perfect body and that's why it is essential to break free from the Iron Maiden ideal. This concern is quite relevant in a culture that treats women's cancers, especially the breast cancer, as a cosmetic problem. However, popular perceptions about plastic and cosmetic surgery do not generate the impression of a painfully restricted body-self image.

The constricted nature of a corporeal identity that 'beautifying' or 'repairing' surgery promotes is hidden under images and strategic verbiage of freedom, informed aesthetic choices and power over one's own life. Ironically, the beauty industry and especially cosmetic surgery repackage certain feminist terminology such as 'autonomy', 'reaffirming control over one's body and one's self' and 'self-empowerment' to justify and promote their products and services. Though post cancer cosmetic surgery has very little to do with curing the disease, it is projected as an essential condition for psychological and emotional healing after a devastating and

disfiguring phase of illness. Choices conforming to patriarchal norms and heterosexist power equations have been packaged in the guise of sovereignty of the self. Studying individual choices without examining the temporality and cultural contexts of those choices would lead to a serious analytic flaw that would make conformity appear as freewill.

A cure that does not heal is indeed a terrible angel. After undergoing 'disfiguring' treatment that saves one's life or offers a temporary cure, a person's attitudes towards her/his altered body and ominous fear of transience (of life, of wellness, of happiness, etc.) determine the degree of healing. A person may feel healed even if not cured of the illness by coming to terms with one's illness, altered body and impending death. On the other hand, despite being asymptomatic after a successful phase of treatment, s/he may not experience 'healing' if the changed body and fear of death continue to haunt her or him.

The transformations after surgery and chemotherapy often trigger apprehensions as to -whether the body is 'desirable' and appealing anymore, especially in the context of heterosexual erotic relationships. Some women get accustomed to the altered body-image and start feeling more comfortable without prosthesis and reconstruction. On the other hand, many women do not opt for breast reconstruction for the fear of being judged as vain and shallow.

It is taken for granted that conformity to standards of bodily acceptability is an essential condition for social and economic mobility. Our bodies are embedded in institutionally bound or unbound disciplinary mechanisms or affected by subtler biopolitical strategies operative in culture. Biopolitical thought projects justice as its goal, yet the major purpose of biopolitics is not to preserve health or justice; it aims at maintaining the institutional, normal, right quantities and kinds of pleasure and pain that maintains societal balance. The concepts of 'species' or 'population' average things and biopolitical strategies produce norms through such statistics. In this context, one should consider the possibilities of asserting radical difference in opposition to the norms of femininity. Susan Bordo rightly warns about the

regulated practices of the self that implicate an internalized biopolitical schema which is more subtle than disciplinary mechanisms.

The cultural paraphernalia of femininity surrounds the bodies of women with normative practices, objects and objectives. When we look at the evisceration of subjectivity, body figures primarily as a medium or text of culture and also as a direct locus of social control that operates through subtle strategies. Human beings master the norms primarily through corporeal discourses and practices; cultural images and imaginings further tutor us in terms of attire, expressions, disposition and behaviour. The complex connection between the representation of women in culture and the everyday practices and expressions of women's bodies and selves are worth examining from the angles of domination and subject formation.

Audre Lorde's critique of women's wig-hunting and prosthetic-breast-fitting frenzy after cancer treatment and Betty Rollin's justification of women's anxiety about their appearance post cancer surgery and chemotherapy illustrate how women who have experienced cancer differ in their priorities and perceptions. The body-self-image is closely linked to one's point of view about the quality of life and wellbeing. Some narrators emphasize the need for research directed towards efficient healing methods and less dehumanizing treatment procedures. Sadly, medicines, surgery, radiation, chemotherapy and other methods used for cancer care may subject a person to more suffering than cancer itself. In the treatment of breast cancer, the transition from Halstead's radical mastectomy (removal of the entire breast, lymphatic tissue in the area, and the pectoral muscle) to moderate contemporary surgical methods such as lumpectomy and reconstruction procedures indicates how the concerns about the quality of life and body-self-image have factored into medical processes and decisions about treatment options.

Betty Rollin's much appreciated and much criticized *First You Cry* discusses how paying attention to trivial matters such as the right kind of wig and prosthesis helped her in diverting her mind from devastating concerns about mortality. Rollin's work was attacked for frankly articulating her concerns about

a changed body, lost breast, sex appeal, and inability to wear bikinis or strapless dresses. Such anxieties seemed to reinforce certain stereotypical views about women's vanity. A surgeon warns: "Avoidance of adequate surgery due to 'feminine whims' might result in a 'dead woman with a somewhat more pleasant-appearing chest wall'" (62). The incapacitating self-consciousness and awareness about her disfigured scarred body made Rollin spend hours putting on make-up; it also affected the relationship with her partner. Still she justifies her obsession with looking good thus: "Scratch most feminists, heterosexual or homosexual, and underneath there is a woman who longs to be a sex object. The difference is, that is not all she longs to be.... For one thing they realize that wanting to be attractive and sexy is human – something that men want too, and nowadays more men are admitting to it" (111).

If all human beings want to be sex objects or expect others to be sex objects, though in varying degrees, one cannot blame individuals for that. A widespread awareness and caution about the forces operative behind the construction of such an attitude is needed. In the present consumer-mass media-patriarchal culture, all live with an awareness of the judging gaze surrounding the self.

Though American Cancer Society's Reach for Recovery Program does a valuable service in contacting women and letting them know they are not alone, Lorde criticizes it for propagating a false assurance and devastating nostalgia for lost breasts. She remembers her post-mastectomy days and the encounter with a volunteer from the programs who showed up with a prosthetic breast and practical advice. Lorde responds hence in her *Journal*: "My primary concerns two days after mastectomy were hardly about what man I could capture in the future, whether or not my old boyfriend would still find me attractive enough, and even less about whether my two children would be embarrassed by me around their friends" (57).

Despite the shift of emphasis from morality to aesthetics in the contemporary times, the formulations around the female body still revolve around the idea of shame. A strong resentment

targeting one's body and inability to feel comfortable about one's body are still prevalent not merely because of the view of flesh as the springboard of desire and hence the seat of moral corruption. With a tutored vigour, we are now inclined to think of fat, body hair, aging, wrinkles, graying, scars, blemishes, amputations, etc. as shameful blots that should be eliminated or mended. I feel that sculpting the female body in order to conform to a cultural norm is strongly a misogynist choice. The loathing for a body that shows any divergence from the projected bodily aesthetic ideal is not less dangerous than the overtly or subtly expressed resentment for free expression of female sexuality. These are modes of control and definitely not occasions for free choice. Women who feel empowered by sculpting their bodies through surgery should realize that certain choices are exercised in a cultural context that endorses such choices and projects them as better than others. In general, absence of breasts is considered to be an imperfection and hence an impediment to a good quality life.

We are in a culture which gauges one's worth and success in a scale of appearance. The neoliberal ethos and the self-help culture promote choices that give one a sense of control and agency over one's life. Healthcare choices are also consumer choices in the current scenario. The nexus between freedom of choice and consumption of medical or cosmetic services is such that the notion of responsibility brings in a new complex problematic. Neoliberalism recommends normalization and responsabilisation of the self in a scenario wherein healthcare amounts to shopping for the best doctors and services. One who chooses is often willing to take the responsibility of choices, being fully or partly aware of the risks involved in a choice. In the 'moral economy' of neoliberalism, educated or informed audacious choices are projected as a sign of self-empowerment. We are in a culture that is capable creating an atmosphere of incessant discontentment with oneself and generate hopes that always loom large in the mental horizon like mirages. We are surrounded by consumerism that never rests from showcasing the means of attaining short-lived contentment till another new ideal appears to haunt us with a new desire and discontentment. Biopolitical strategies and technologies of the self implicate a control that does not make

itself felt on the self. In other words, the self does not realize that its under the sway of a normalizing mechanism. Neoliberal citizens deem it mandatory to improve and manage the bodies and selves and are blissfully oblivious of the practices of the self in alignment with the notions and norms operative in culture. Submitting oneself to the risks of cosmetic surgery, ironically, turns into a valiant act that enhances self worth; living with an unattractive body is an 'ethical failure.' Body is considered the launch pad of self transformation. So we are told that risks are worth taking as the body is a plastic and flexible entity fraught with endless possibilities of improvement.

Lorde had a strong conviction that women should make themselves capable of taking informed decisions so that they are able to be immune to the exploitative aspects deeply entrenched in highly commercialized healthcare practices. She set out on an epistemological journey of reading and research on cancer which also involved conversations with doctors, medical professionals and cancer patients. Gathering reliable information and knowledge about healthcare procedures and treatment options for arriving at intelligent decisions for oneself is important. To accomplish this, not only the expert professional opinion, but also the points of view of those who have gone through the ordeal of illness and suffering are of use. Recording one's story of illness thus becomes for Lorde a dutiful act performed for others. For accomplishing a sense of mastery over one's body and life, awareness, empathetic understanding of others' life-worlds and sharing of lived experiences become a prerequisite. Dealing with despair and anger on witnessing the sad state of healthcare for women, Lorde ruminates on issues like women's body-self-image and identity defined by and limited to body. She realizes with horror how women become active agents in the construction and sustenance of disciplinary mechanisms and practices detrimental to their bodies and selves. Lorde calls for 'radical difference' as opposed to passive conformity for women to challenge the socio-cultural control and disciplining of their bodies.

Audre Lorde thinks that one 'disfigured' of the body has a shock value due to her radical difference from the norm and so women with breast cancer should join together to influence the

policy-making process regarding healthcare and cancer research funding. She expresses her resentment to the tendency to cover up differences as she considers this attitude to be complementing a highly demeaning normalizing mechanism. The mask of prosthesis and wigs isolate women in their own private shells of suffering, closing all opportunities of sharing their concerns with other women who are in the same situation. Sharing one's experiences of pain, fear and suffering through biographies and conversations is a kind of advocacy for policy change. Lorde suggests that rather than hiding behind smug wigs and prosthetics, women should act more responsibly towards their vulnerable fellow beings. She imagines a powerful possibility: "What would happen if an army of one-breasted women descended upon Congress?" (*Cancer Journals*, 15) Lorde reminds that the prosthesis is a cover up and a standardizing strategy in a society wherein women are judged for their appearance. She points out: "We are surrounded by media images portraying women as essentially decorative machines of consumer function, constantly doing battle with rampant decay.... As women, we fight this depersonalization everyday, this pressure toward the conversion of one's own self image into a media expectation of what might satisfy male demand (Ibid, 66). Prosthetic breasts hide the suffering and hence invisibilize the grave problem of increasing incidence of cancer that needs more research directed at prevention, more humane modes of treatment and healing. Plastic surgeons who perform reconstructive surgery in the name of 'quality of life' reinforce the ideal of normal femininity. Referring to the possibilities of healing oneself, Lorde emphasizes the need to love one's altered body, accepting it as it is and also receiving empathetic love from women around her. Being a black, lesbian poet activist, Lorde affirms the need for visibility and voice; silence and covering up the absent breast with prosthesis do not empower or liberate.

Gillian Rose does not have a harsh view of the healthcare system and her critique is mild and full of understanding. She feels she had been treated well even though a cure was not arrived at. Her quarrel is with the way in which death and illness are perceived to be extrinsic to life. One may look at tragedy as part of our being and living and harmonize it with the everyday existence.

As she came to know that she was going to die, Rose feels neither rage nor despair. In *Paradiso*, Rose speaks of her doctors with appreciation and understanding, specially remembering Dr. Grove. The text has chapter titled “Dr. Grove or Goodness” in which Rose ruminates on issues like healing and cure. As a philosopher, her vocation has been ideally to tend the soul and the doctor is someone who is supposed to heal the body. She realizes that though her cancer cannot be cured and is spreading all over, she can still feel well and at peace. Dr. Grove looks at the grim reports of the advancing ovarian cancer and still does not want to challenge the autonomy of the patient. Nor does he want Rose to put her body through more and more tormenting treatments. He invites Rose to carry her medical condition as *autopoiesis*, which to Rose means continuous expansion and exploration of the self. She feels grateful to the doctor for making her his co-agent in treating her.

Like Audre Lorde, Beauvoir, Sontag, Gubar and Ensler use writing as a mode of critique and activism by drawing attention to the inadequacy of medical and pharmaceutical research as far as cancers of women are concerned. Even in the 21st century, accurate diagnosis, less painful treatments and more reassuring survival rates seem to be difficult, if not impossible for a deceptive ailment and ‘silent killer’ like the ovarian cancer. The remission is usually brief as the cancer often recurs and metastasizes with a vengeance. Even now, there is no foolproof detection protocol for the ovarian cancer, as a result of which many women are diagnosed in advanced, even terminal stages.

Gubar is horrified by the lack of knowledge and misinformation women have about ailments and their body in their general and cancer in particular. She emphasizes in the *Memoir* that women should pay attention to their bodies, be aware of the risks of medical treatment and the role of their heredity in diseases like breast and ovarian cancers. Although the ovarian cancer presents symptoms, they are often ignored and misinterpreted. Symptoms like bloating, fatigue, a feeling of satiety, indigestion, recurrent back, abdominal or pelvic pain, urinary frequency, flatulence, irregular periods, spotting, cramping, constipation, shortness of breath, pain during intercourse, or incontinence, Gubar points

out, are common in women and overlooked by most. These symptoms are dismissed as baseless anxieties, attention-seeking behaviour, and signs of hypochondria or misdiagnosed as other diseases. There are several advocates for breast cancer – most of them being survivors. But there are not many ovarian cancer advocates, because only very few manage to survive the disease. Susan Gubar looks at her ovarian cancer experience to examine the sociology and politics of women's illness and intimate experience of pain and suffering. Though Gubar understands the plight of women who feel inhibited to talk about the altered body-self image, devastating side effects of chemotherapy, appearance-related issues and decreased sex-drive, her own narrative has a disturbing starkness. She has written it to inform and awaken.

Memoir of a Debulked Woman is a strong indictment against the medical establishment; yet Susan Gubar is grateful for the efforts and care provided to her by doctors, nurses and other medical professionals. After an incapacitating oncological debulking surgery, Gubar had to undergo six cycles of chemotherapy following the warning of the oncologist that without the standard treatment, her death was only a few months away. Gubar's debulking operation left her colon punctured which necessitated insertion of drains through her right buttock. She had to attach on her body an external receptacle that accumulated excrement. Gubar compares the debulking operation, Mother of All Surgeries, to gutting, evisceration and vivisection or disemboweling performed on a live human being. This procedure reduces women to docile and passive beings on the operating table as they cannot participate in surgical decisions such as attaching colostomy bags. She writes candidly about leaked excrement fouling her body and the slimy rivulets of shit coagulating under her jeans when the colostomy bag malfunctions. She expresses her indignation for dehumanizing 'standard medical procedures' that affect the quality of life negatively to which the employed and the insured are subjected to. She also grieves over the dreadful fates of those not covered by insurance to receive such 'life-saving', yet humiliating interventions. Gubar asks why there aren't any methods for treating female cancers other than painful debulking, mastectomy, ovariectomy (oophorectomy) and hysterectomy — often followed by radiation and chemotherapy.

Debulking surgeries are often suboptimal, meaning a few cancer cells may remain in the body, making chemotherapy necessary. Chemotherapy for ovarian cancer may have terrible side effects: nausea, diarrhea, constipation, weight loss, hair loss, numbness of hand and feet and the like. Gubar does not provide false reassurance in her *Memoir*. On the contrary, she portrays nuances of physical sufferings without using a clichéd brave and jubilant tone of triumphalism which is found in abundance in survivors' narrative retrospections. All surgeries and treatments for cancers are, perhaps, biopolitical strategies of corporeal control in the guise of being beneficial or lifesaving for the patient. Gubar's body, made more vulnerable and less immune due to chemotherapy, suffered painful infections and considerable damage. In the *Memoir*, she uses the term "lo-con-ocology" (with emphasis on 'con') to highlight the dilemmas of patients and doctors who are compelled to follow certain medical protocols knowing fully or partially how damaging and painful these could be for the patient's body. Illness is an insidious presence that gives the ultimate control over the patient's body to the doctor – the one who has the knowledge of the disease can objectify the one who suffers from the disease. Though the doctor, through diagnostic techniques such as the blood count, X-ray, or CAT scan, directs the penetrating medical gaze into the objectified body of the cancer patient, the gaze does not gauge the pain experienced by the patient. The verbal report of the patient about one's difficulties is often considered unreliable and exaggerated, hence ignored by medical practitioners. A patient's cancer might be made tangible through diagnosis, but the accompanying 'invisible' pain is not always given proper attention, resulting in the under-prescription of medication.

In Eve Ensler's *In the Body of the World*, a blatantly stated premonition that virulent cancer, increasing violence against female bodies and destruction of nature indicate the beginning of an end – end of the body, end of humanity and end of the green planet – rings through the narrative like menacing leaden knell. Ensler expresses her angst, reiterating the association between her cancer, murderous cruelty against women and nature with an emphatic insistence on the menace of being

wiped out and silenced. Unlike most of the cancer narratives that give accounts of the self, going through a perilous phase of life and confronting body's betrayal and impending mortality, Ensler tells the story of her uterine cancer (metastasized in the liver) by embodying the illness and embedding it with layers of narrations about the epidemic of violence that mars and destroys human bodies and the repeated violation of the body of earth by unbridled material lusts. The narrative abounds with images of ugliness for their shock value. Ensler's abdominal cavity full of dark pus immediately evokes an association with the oil spill in the Gulf of Mexico. Chemotherapy destroying healthy cells along with malignant cells reminds her of the attacks on Al Qaeda that destroy innocent civilians as well. The unexamined celebration of human optimism, triumphalism on conquering the illness and formulae for inspiring other 'victims' and 'survivors' are conspicuously absent in the *Memoir*. While she gets a durable remission due to the advanced diagnostic and treatment procedures, Ensler sadly mourns underprivileged women who die miserably in the absence of proper medical care. Ensler pays little heed to Susan Sontag's caution against metaphORIZING illness; she revels in the ironic directness of metaphors and makes good use of metaphors' shock-value as political statement. The *Memoir* presents cancer with all its harrowing details and describes its destructive proliferation in the body of the woman-narrator. The lonely inexpressible moments of pain, ugliness of the body marked by indelible surgical scars and voids left by amputated organs, humiliation of the body by denying it privacy and autonomy, leaking into the world as smelly fluids and feces – these familiar scenarios of cancer and its treatment turn into metaphors for rampant brutality against women and earth depicted as a feminine entity.

Eve Ensler raises a significant question whether women's cancers are trauma babies or the effect of 'somatizing' their repressed suffering. 'Congo stigmata', a sign that the suffering women of Congo bear within them has entered the author's corporeality and manifested as illness. Ensler has an inexplicable rare symptom similar to what rape does to the women of Congo. The cells of endometrial cancer formed a tumor between the

vagina and the bowel that on being surgically removed leaves a hole. Ensler delineates the holes that prevent life from becoming whole: the black hole created by gang rapes in the vaginal lining of Congolese women, voids in her own body after the cancer surgery, rip in the ozone layers, mining pits, holes in the memory left by trauma, and holes in the social fabric torn apart by incest... all contributing to the devastating experience of alienation from existence.

Beauvoir's portrayal of medical professionals in the text is done through some telling moments that speak volumes about their arrogance, insensitivity, condescension and egoism. She emphatically suggests that doctors should be able to understand their profession in a way that is more than what standard text books would teach them. The first instance is about their regular doctor who took offense for nothing. When Maman fell unconscious, Dr. Lacroix who used to stay at the same apartment building rushed to assist her. This upsets the physician whom the old woman used to consult regularly and was so comfortable with. That he was not contacted immediately offended the regular doctor who is referred to as Dr. D and he refused to see his patient. Doctor with an unresponsive face and remarkable expertise in resuscitation, Dr N "smart, athletic, energetic, infatuated with technique" is so proud that he had been able to revive Maman from something that appeared to be a coma or death. For him, this feat was yet another challenging experiment in which the patient does not matter at all. He is devoid of emotions or sensitivity and functions with the precision and tireless meticulousness of an efficient automaton. He is so tactless and dismissive in handling the anxious queries of Beauvoir and her sister that they find him intimidating. Resuscitation was brilliant, almost miraculous. But the doctor did not take into consideration that prolonging Maman's life would only mean lengthening her torment as her disease was at an incurable stage. On seeing their mother connected to tubes and medical equipments, which reminded them of torture devices, Beauvoir and her sister earnestly ask the doctor whether it is of any use as there is apparently no hope of a cure. The doctor's reacts with a withering look and reminds the sisters that he is giving their mother the standard treatment to be

given in such a scenario. His subsequent response is even more unfeeling and supercilious:

“Would you like me to have left that in her stomach?” said N aggressively, showing me the jar full of a yellowish substance. I did not reply. In the corridor he said “At dawn she scarcely had four hours left. I have brought her back to life.” I did not venture to ask him “For what?” (27–8)

At the hospital, with horror and helplessness, Beauvoir realizes how treatment procedures are painful without any consideration for the quality of life of the patient. A common grievance among cancer patients is that pain medications do not always effectively manage the excruciating pain one suffers from illness and treatment procedures such as surgery, radiation and chemotherapy. The doctors under-prescribe pain medication because of concerns such as addiction, dependence and side effects. Beauvoir narrates an incident that happened at the hospital which reveals Dr. N.’s callousness:

She was as much afraid of the nightmares as she was of pain. When Dr N came she begged, “Let them inject me as often as necessary” ... “Ha, ha, you are going to become a real drug-addict!” said N in a bantering tone. “I can supply you with morphia at very interesting rates.” His expression hardened and he said coldly in my direction, “There are two points upon which a self-respecting doctor does not compromise—drugs and abortion” (79).

Another doctor, Dr P is more humane as he did throw his weight around and was willing to talk to the patient and answer her questions. He could give confidence to the patient and the caregivers though the suffering of Maman was not alleviated. Another important yet much neglected issue in healthcare is communication. Beauvoir is deeply disturbed and overcome by guilt because important details about her illness and treatment were withheld from her mother. In the 1960s doctors and relatives believed in withholding information from the person who is ill so that the person is able to cling on to optimism. This sort of non-disclosure of diagnosis and prognosis is not considered ethical by both medical practitioners and caregivers in many countries

in contemporary times. When a patient comes to know of the seriousness of the illness and the bleakness of one's situation, fear and hopelessness may make the healing more difficult. That is the reason why the relatives wish to keep the details of illness undisclosed to the patient.

Maman was neither informed nor was her opinion sought while she was subjected to a painful surgery. She did not know that she had cancer. Beauvoir's was in a state of confusion and moral dilemma. Her mother wanted to live and often expressed the haunting fear of death. She was going through the treatment with a good faith that she will have many more years to live. She looked at the treatment, however painful it was, as a temporary trouble that would ultimately prolong her life. Under such circumstances, Beauvoir shares her suffering as a caregiver: "And I too had a cancer eating into me—remorse....And I had not prevented anything. Often, hearing of sick people undergoing a long martyrdom, I had felt indignant at the apathy of their relatives" (57). Sartre tries to make her see things from another angle: "You were beaten by technique: and that was fatal" (50). The much praised efficiency of surgical procedures, mechanical interventions and expert specialists fill the patients and their relatives with hope, urging them to subject the patient to endless and torturous treatment.

The passivity and ignorance of the patients of her time was such a disturbing sight for Beauvoir: "One is caught up in the wheels and dragged along, powerless in the face of specialists' diagnoses, their forecasts, their decisions. The patient becomes their property: get him away from them if you can! There were only two things to choose between on that Wednesday—operating or euthanasia" (56). The doctors come up with ready explanations using a condescending tone to silence the patient and the relatives. The dear and near ones also try to condemn the patient to silence by not allowing her/him to express the anxieties, fears and doubts, smothering everything under unsure assurances. The patient is forced to seek refuge in false hopes. It is in the *Memoir* that Beauvoir explains how she felt she was part of a plot for betraying her mother:

Her desperate eagerness to get well, her patience, her courage—it was all deceived. She would not be paid for any of her sufferings at all... Despairingly, I suffered a transgression that was mine without my being responsible for it and one that I could never expiate (58).

Narratives are useful for understanding one's illness and explain it to others. The need for the seriously ill is not limited to expert care and medicines. They may need others to realize that illness has done something to the deeper self, by taking away something from it or leaving it marked. There are times when sadness and hopelessness assault the ill and sharing becomes important. Stories of illness can turn into a sinister force by invoking closure and finality; they can impose meanings and make communication and healing difficult. The demands for constructing a structured narrative which is intelligible to others will subdue the enigmatic, chaotic and inarticulate nature of illness as a lived experience. Instead of bringing the self close to its own experience, writing a narrative may take one to distance and detachment. The stories of illness may be, metaphorically speaking, co-authored by caregivers, doctors, nurses and several others who can influence one's approach to the experience of illness and suffering, transforming the self's experience into somewhat unidentifiable unfamiliarity. Narratives may tempt one into hiding behind excessive rhetoric, editing out experience and adding detail extraneous or apparently irrelevant to the self and illness. Illness necessitates telling stories because narratives are used to hold one's life, broken apart by illness, together and make meaning and even purpose out of it.

Conclusion

It is high time that the importance of narratives is recognized by doctors, nurses and social workers. Understanding the plights of patients from a human rather than scientific perspective would help in enhancing the quality of healthcare. Doctors and nurses may then view their patients with more humility and concern. For healthcare professionals and administrators, it requires the ability to interpret, internalize, and get involved in the stories

of the ill to put to use the illness narratives to create a context for better and humane healthcare. Moreover, narratives that speak freely of the failings and limitations of medical care would prompt the medical experts and professions to self-reflection and self-correction.

Illness makes the narrator explore the terrains of profundities and banalities of life. Writing on it translates into activism when the ripples of thoughts created by it slowly bring about a sea change in one's own life, family, culture and society. In the concluding chapter of *Fractured Borders: Reading Women's Cancer Literature*, Mary Deshazer argues:

Women's writing about cancer undertakes four important kinds of work that facilitates cultural change: it foregrounds ill women's agency than their victimization; it celebrates feminist themes of affiliation, resistance, and new knowledge; it offers opportunities for healing to both writers and readers; and it provides strategies for mourning and commemorating the women whose lives have been lost to this illness. (261)

The act of writing the memoir of an illness, apparently, is an amalgamation of memory and desire revolving around embodied experiences. It is also political to a great extent. In *Treatments*, Lisa Diedrich argues that experience is not about the past alone; it takes possible futures into consideration (5). Memory and desire are inextricably entangled in the subjective- linguistic domain of narratives. Illness and pain are states in which one becomes sharply aware of one's embodiment; body otherwise does not intrude much. Gadamer is right in his observation that "illness can make us insistently aware of our bodily nature by creating a disturbance in something, which normally, in its very freedom for disturbance, almost completely escapes our attention" (*Enigma of Health* 73). Desire and memory enter the awareness of body so conspicuously when pleasure reaffirms body's being or pain, illness, and impending death threaten body's annihilation. Disease not only makes one conscious of the existence of body, it also compels many to look back at their lives and choices made. Desire is a noticeable element in illness memoirs - be it the desire

to live and continue life's work or the desire to wear, without being an anomaly, a strap sleeve top or a tight T-shirt after a mastectomy. In the case of illness, processes of memory and desire straddle myriad aspects deemed to be sublime or trivial. Narrativization becomes a part of the performative dynamics of being ill. Writing perhaps holds together the disjointed self of the ill person and saves the writer from total disintegration and dissolution. It is a way of confronting the reality of illness, and an attempt to cope. Memories of suffering and damage done to the body are perhaps the best weapons to fight against social ills, malicious cultural attitudes and injustice of the medical field.

The way a doctor or a healthcare professional understands a patient's body, sickness, disease causality and mortality may be incompatible with the patient's interpretation of one's own condition. A doctor may be blind to the guilt, fear, and shame that a patient suffers along with illness. Such gaps in mutual understanding could be bridged with effective communication. A doctors' familiarity with interpretations of being ill from the points of view of patients is useful in cultivating the habit of interpathy. Art, literature, cinema and performance are effective means for making the patients' perspectives available to doctors.

There is a possibility that the narratives of doctors and the narratives of patients, however different might they be in terms of tone, content and core issues, could inform each other. It is essential to acknowledge reciprocity in the narrative practices and medical practices. It is not restricted to dialogue and conversation, but joining the efforts and working towards common goals. The body, illness and treatment have become themes for literary and artistic expressions. The impact of literature and art on medicine and healing is opening up as a promising field of investigation. We keep hearing about narrative healing and art therapy. More research along these lines is required and underway.

Unfortunately, more often, instead of discovering modes of dialogue, the narrative exercises become one sided - a monologue of either the doctor or the patient. When it happens, the benefits of combined knowledge and experience are lost. There comes a state of animosity in which the doctor dismisses the patient's

version of the story of illness as immaterial and the patient grieves at the insensitivity of the doctor who refuses to engage with her/his narrative of illness. Many doctors, in the height of arrogance and authority their education and training give them, do not find the patients' narratives to be enriching or supplementing their knowledge in anyway. Kathryn Hunter points out that there is a certain degree of 'narrative incommensurability' in the different ways in which doctors and patients describe and interpret illness.:

The patient's account of illness and the medical version of that account are fundamentally, irreducibly different narratives, and this difference is essential to the work of medical care. Sick people who seek a physician's advice and help are in quest of exactly this difference, for physicians are believed not only to know more about the body but also to see its disorders clearly and without shame. Yet because it is scarcely acknowledged by either patient or physician, the difference between their accounts of the patient's malady can warp understanding between them. (*Doctors' Stories* 123)

Narratives about illness can re-humanize the healthcare profession. Narrative research is a rich source of insights for a sensitive understanding of the notions of self and identity. When people tell their stories and narrate their experience, they also tell us who they are. Narrative research in healthcare has to turn its focus more to what illness, injuries and disability do to an individual, to one's sense of the self and identity. Narrative practices have effectively challenged the narrow positivism of the social sciences and still narrower biological determinism of medical sciences. As we have already seen in the study, by providing a tool of resistance for the oppressed groups, narratives can turn into a strategy for bringing about social change. Medical studies have begun to take narratives and life-stories into account in a reassuringly robust way though much more attention can be paid to narrative research in the years to come.

My study is inspired by optimism and faith in the power of narratives based on life worlds and lived experiences. I strongly believe that 'writing for righting the wrongs' is not a cliché slogan

or an unrealizable dream. The vitalizing and nurturing power of letters is not a inane romanticized idea. In the histories of movements for facilitating a more just and egalitarian state of affairs and safeguarding human rights, writing, especially auto/bio-graphical narratives have played a crucial role. Feminist movements all over the world have been reinforced, enriched and made more intelligible by life writing. History has witnessed the cumulative effect of narrative practices on those who face discrimination, humiliating restrictions, injustice and exploitation. On being deprived of freedom and the right to dignity and equality, sharing of one's stories of life has worked as a cementing factor and a clarion call for collective action. In feminist and dalit movements, auto/bio-graphical accounts are a force to reckon with.

Feminist scholarship in the area of illness and embodiment is substantial and diverse, with several new works being added every year. The epistemological interventions and activism across the globe in the sphere of healthcare have helped in dealing with patriarchal control over women's bodies and misogyny prevalent in the medical profession. Patriarchy and misogyny have influenced the perspectives and policies concerning healthcare in general and management of illness and rehabilitation for women in particular. Gender bigotry of bioethics and in charting out healthcare policies are disconcerting as the rights of women patients are not understood or ensured with gender-sensitivity. Many matters of crucial importance in healthcare are determined with very little understanding of women's selves and needs. Social and religious prejudices have percolated into even the clinical understanding of women's bodies and selves. Healthcare professionals often treat women as lesser beings or do not consider them as independent and intelligent individuals who have a right to take decisions about their own bodies and treatment options. The feminist interventions in the domain of healthcare have undoubtedly effected changes in favour of women. But the efforts have not yet reached fruition as there is still so much to be done and issues of importance to be addressed. Illness narratives and similar forms of life writing and writing about life worlds built around healthcare practices make a record of path-breaking struggles by

individuals that have made it possible to ensure some degree of justice and equality for women in the field of healthcare. Though she is not fooled into thinking that the feminist fight is over in the arena of healthcare, Rita Charon is quite optimistic about the power of concerted narrative activism by women:

The very terms of engagement of feminist studies arose from the medical sphere—the panoptic gaze, the clinical objectification, the machine of power. As the *ur*-narrative of women’s struggles against male dominated systems of power, medical struggles repeat and reproduce the consequences of the dominant discourse over enforced silence, of the knot of knowledge and power against ignorance and weakness, and of the advantage that can be taken of human need (*Gender Scripts in Medicine and Narrative*, “Preface” pp xiv-xvii, xv)

Narratives about illness by women have questioned unfair healthcare practices that put women in a position of disadvantage and inequity. The power of texts, cinema, works of art and many such modes of expression and sensitization for addressing epistemic and physical violence against women should not be underestimated. Disregard for women, invisibilizing and silencing them and paying no attention to their views still thrive in societies across the world. This tendency can be sabotaged if women find their voice and mode of expression, write their own stories and scripts, and create forums where their points of view would be heeded and respected. Women can make themselves visible and audible by expressing themselves through texts and art. The texts in this study illustrate the potential changes in the realms of ideas and practices that life writing can bring about. The strategy of turning textual/ narrative practices as interventions for social critique and social change is illustrated by the texts selected for this study. On reading them, at least some women who undergo experience of illness may share the authors’ fury against injustice, violence and bigotry embedded in healthcare practices and determination to bring about positive changes.

Writing and speaking about illness is believed to unburden the load of negative emotions and anxieties of the patient to some

extent. Life writing about illness keeps ideas in the air which have the power to trigger corrective actions. The domain of narratives is not cut off completely from the domains of performance and activism. Powerful narratives have strengthening and liberating effects on the writer and community of readers. The very act of writing and reading narratives of life and life-worlds concerning illnesses may turn out to be the first step towards inspired actions aiming at preventing injustice and protecting women's rights. Life-narratives open a possibility of making women visible and heard, and a collective force to reckon with, in a world that at times pays no heed to them.

Narrative practices have the power to facilitate patient-centred health care, which demands considering patients as people and autonomous subjects. Patient-centered healthcare is necessary to promote purposeful beneficence and to prevent deliberate or unintentional harm. Patient-centred healthcare has a holistic biopsychosocial approach in which the doctors and other healthcare professionals are concerned not only with the physical manifestations of the disease and its management, but the psychological and relational aspects of being ill. Illness as a solitary experience has an embedded narrative impulse in it. By sharing the lonely moments of illness through writing, one reaches out to potential companions in suffering. Those who try to interpret illness narratives can sometimes vicariously experience the plight of the ill to some extent. Life writing about illness provides explanatory models to usher a meaningful biopsychosocial approach into healthcare. Narratives of illness put in place a framework for healthcare professionals to reflect upon a patient-centred approach to healthcare in which decision making about treatment procedures is also a shared exercise. That is to say that the patient who gives an account of oneself is not treated as an ignorant and vulnerable subject who is not to be accounted for. The patient, by giving an account of oneself demands more accountability from medical professionals.

In patient-centered healthcare, the patient is not merely a consumer of healthcare, s/he can co- produce the conditions for care, or in other words, exercise the right to choose the terms of care. For that, it is necessary for the patients and healthcare

professionals to educate each other. In this process which demands understanding, sharing and access to information, the role played by life-narratives is significant. Narrative agency hence leads to more substantial forms of agency and autonomy.

The narratives of illness discussed in this study illustrate that women are not always passive ‘victims’ of regulatory strategies of healthcare biopolitics. They can engender an informed and collective social critique and resistance.

End Notes

- 1 Quoted in the “Introduction” to *Narrative Research in Health and Illness*, (Eds. Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans. Massachusetts: Blackwell Publishing, 2004), pp 1-20, p 3
- 2 See *The Emperor of All Maladies: A Biography of Cancer*, 41
- 3 Sigrid Nunez on Susan Sontag, by Thessaly La Force (<https://www.theparisreview.org/blog/2011/04/04/sigrid-nunez-on-susan-sontag/#more-13776>, accessed in September 2016).
- 4 Quoted in <http://www.newyorker.com/online/blogs/books/2012/06/susan-gubar-memoir-of-a-debulked-woman.html> (accessed on 10 September 2012)

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