Chapter 1

Introduction

> Almost every illness story carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly. Extending this metaphor describes storytelling as "repair on the wreck"...
>
> Arthur Frank, *The Wounded Storyteller*, 1995

> Breast cancer is a disease which both threatens a woman's life and disrupts her physical integrity as a woman, often in starkly visible ways...breast cancer is not only a health crisis but, a crisis which could end in death or, at best, a violation of her understanding of herself as a woman"
>
> Anne S. Kasper, "A Feminist, Qualitative Methodology," 1994

1.1 Scope of the Study

This thesis presents a comparative analysis of six Indian and American breast cancer memoirs with three critical considerations:

1. How a breast cancer diagnosis is a life-altering event that disrupts nearly every aspect of a patient's life, and how this disruption occurs on multiple levels—physical, emotional, social, and financial—and can have both immediate and long-term effects
2. How the experience of the disease can vary significantly between women in different cultural and geographical contexts, such as Indian and American women.
3. How the coping strategies employed by the narrators battling breast cancer reveal the existence of an inherent coping mechanism that has universal

> characteristics, even though specific strategies may vary across cultures, individuals, and contexts and how this inherent mechanism represents a fundamental aspect of human resilience, allowing these individuals to adapt to and manage significant disruptions in their lives.

This thesis expands the concept of ‘biographical disruption’ developed by Michael Bury in his 1982 article “Chronic illness as biographical disruption” to explore how a chronic illness like breast cancer also leads to biographical disruption causing significant changes in an individual's life, biography, perception, and interpretation. By broadening the concept of biographical disruption, this thesis aims to offer a deeper understanding of how breast cancer impacts women across different cultures. This expanded perspective would emphasise the significance of considering cultural, social, economic, and healthcare-related elements in shaping the experience of a chronic illness like cancer. It would provide valuable insights for academic research as well as practical healthcare approaches. Similarly, the thesis looks beyond the coping framework proposed by Richard Lazarus and Susan Folkman (1980, 1984, 1988, 1993, 1999) to explore whether the coping strategies employed by the narrators in the study entail an inherent reconstruction mechanism through which they explore a more holistic and nuanced view of a coping mechanism that considers a wider array of factors, including cultural, societal, clinical, and existential dimensions.

Breast cancer, like other chronic illnesses, not only changes the course of patients' lives but also presents numerous challenges in their daily lives. Breast cancer narratives are those illness narratives that reflect the physical, psychological, and sociocultural burden patients encounter after the diagnosis of breast cancer. The physical burden includes mutilating the body, which disrupts the womanliness that is associated with female identity. The physical changes in breast cancer also induce psychological turmoil as patients experience an enormous amount of fear, shame, anxiety, and guilt which are commonly manifested while traversing the path of illness. Both the physical and psychological burden are also interlinked with the socio-cultural aspects of breast cancer. Patients' struggle with biographical disruption, their expression of emotional challenges as a manifestation of the disruption, and their possible venture at coping with the life-altering changes are the three important aspects which construct the scope of this thesis. The socio-cultural impact of breast cancer varies between Western and Indian cultures, as well as among different economic statuses and social strata. Due to these variations, the psychological impact also varies significantly, as individuals cannot overlook their socio-cultural background and beliefs about the illness and healthcare. The scope of this current thesis is also to look beyond the vulnerability of breast cancer as a form of biographical disruption and its aftermath. Specifically, it engulfs the differences in the cultures of expression in both America and India as the patients participate in the process of shedding the burden. The thesis attempts to discover the patients' endeavours at moving forward after shedding the different kinds of physical, psychological, and socio-cultural burdens.

1.2 Illness and Narratives

While struggling with an illness, individuals are particularly inclined to tell stories about their suffering and to locate their present as a vital part of their life stories. Illness is generally understood as a liminal period and narrating illness leads to both the construction and the presentation of self in front of others (Levy, 2005, p. 9). The first major instance of a published narrative on one's experience of illness is Virginia Woolf's "On Being Ill" (1926). In her ground-breaking essay on illness, she has mentioned that illness had not been considered the prime theme of literature in the 1930s among the other themes like 'love, battle and jealousy' (Woolf, 1926, p. 32). According to Woolf, there are some scattered examples of literature in Proust and Thomas De Quincey that have attempted to narrate about the body in place of the mind (Woolf, 1926, p. 32). Sarah Pett in her doctoral thesis "Reading and Writing Chronic Illness, 1990-2012: Ethics and Aesthetics at Work", has established the fact that the twentieth century has seen a sudden growth in the literature dealing with illness and by the twenty-first century life-writing has proved to be a well-developed genre (Pett, 2014, p. 6). Before Woolf, the instances of personal illness narratives (Samuel Johnson's and Frances Burney's letters, Alice James' Diary) were not circulated widely among the public and had remained in the private domain (Pett, 2014, pp. 6-7). According to Pett, the journey from the private to the public can be marked only in the second half of the twentieth century through Sheila Rothman's *Living In The Shadow Of Death: Tuberculosis And The Social Experience Of Illness In America* (1995) and Ann Jurecic's *Illness and Narrative* (2011) as they were the first published illness narratives (Pett, 2014, p. 7). Autobiographical narratives are always seen as reflections of lives as Jerome Bruner in his article "Life as Narrative" has mentioned that both 'narrative imitates life' and 'life imitates narrative' (Bruner, 2004, p.692). Virginia Woolf has talked about how patients see life differently while experiencing illness. According to her, people often switch from reading poetry to prose because, during illness, senses dominate over reason. Therefore, illness is called the 'kingly sublimity' because it takes us to the other world or helps us to create a new world of our own out of the mundane, isolated, and vulnerable reality of illness (Woolf, 1926, p. 42). Though Woolf in her essay "On Being Ill" has highlighted the problems and struggles faced by individuals and how their lives change their worldviews after the detection of the disease, although she has not mentioned any coping strategies used by the people of her culture (Gygax, 2013, p. 2). There are many scattered earlier occasions of narrating illness using literature as a medium. For instance, the English metaphysical poet John Donne wrote the prose work *Devotions upon Emergent Occasions* (1623) while recovering from typhus or relapsing fever and reflected on the parallels between his physical and spiritual illnesses (Pinka, 2024). Further, Charles Lamb, in his 1833 published essay "The Convalescent" uttered his personal experience of sickness and recovery from it. Lamb, with his distinguished humour, has explained the positive aspects of illness with which a person gets all the attention and extends his thoughts to himself. He has used illness as an armour to stay away from worldly duties and has said that the "supreme selfishness is inculcated upon him as his only duty" (Lamb, 1833, p. 30). The person completely focuses on himself and becomes 'his sympathiser' (Lamb, 1833, p. 30). Though the person tries to find ways to recover from sickness; he loses the attention, care, and dignity of a kingly gesture after getting the convalescence (Lamb, 1833, p. 31). The eccentricities associated with the understanding of illness have been well drawn by Arthur Kleinman who considers 'illness' as 'polysemic or multivocal' because "illness experiences and events usually radiate (or conceal) more than one meaning" (Kleinman, 1989, p. 8). Every patient's personal illness experience has different layers of meaning, and each patient's story is different from others. However, Kleinman believes that every chronic illness follows some patterns where it oscillates between 'periods of exacerbation' and 'periods of quiescence' (Kleinman, 1989, p. 7). As a long-term suffering, every chronically ill patient experiences a swing between ‘amplification’ (involved with ‘disabling anxiety, giving up’) and ‘damping’ (involved with ‘strengthened social supports, enhanced sense of self-efficacy, and rekindled aspiration’) (Kleinman, 1989, p. 7). Therefore, the trajectory of chronic illness is intimately assimilated into one’s life course in such a way that it is almost inseparable from life history (Kleinman, 1989, p. 8).

When the accounts of living with an illness or even dying of an illness are recorded by the patients themselves, they are known as pathographies, or autopathographies. In her 1993 book *Reconstructing Illness: Studies in Pathography*, Anne Hunsaker Hawkins has explained pathographies as biographical or autobiographical narratives about illness, treatment, or death (p. 1). She posits how mythic thinking pervades illness narratives. According to her, mythic constructs not only organise the patients’ understanding of their illness but also influence their interaction with the institution of medicine and their expression in the form of narratives. According to Hawkins, myths are formative in structure and they also help create order out of chaotic situations appearing from chronic illness. Pathographies are mainly concerned with the attempts of individuals to orient themselves in the world of sickness - the world called by Susan Sontag the ‘kingdom of the sick’—to balance self and reality, and finally to arrive at an objective understanding that occurs between experience and experiencing self (Sontag, 1978, p. 3; Hawkins, 1993, p. 2). Pathographies also provide the readers with ‘cautionary parables’ that help them understand the situation when their ordinary life suddenly collapses (Hawkins, 1993, p. 2). In the 1980s, there were three subgenres of pathographies found as evidence of recording one’s illness experiences - didactic pathographies, angry pathographies, and positive pathographies. First, there are didactic pathographies that are read as guidebooks to find suggestions for good doctors, healthy lifestyles, and others (Hawkins, 1993, p. 11). Secondly, there is a very commonly found subgenre called angry pathographies as it is mostly intended to expose and denounce atrocities in the way illness is treated in the American context (Hawkins, 1993, p. 6). Another subgenre of positive pathographies of that period bristle with holistic and alternative therapies - "therapies ranging from such relatively conventional practices as attention to diet and exercise, acupuncture, and visualization exercises to more unusual treatments: the use of quartz crystals, lucid dreams, and various naturopathic remedies" (Hawkins, 1993, p. 9). The angry pathographies mainly focus on 'doctor bashing' but the other positive pathographies are more concerned with a positive approach towards physicians along with alternative therapies. Therefore, be it any of these, pathographies have a common intention of healing the patient-narrators by growing the will to live for themselves by creating an interrelation between body and mind (p. 9).

1.3 Growth of Medical Humanities

The importance of humanities is felt across a whole range of healthcare disciplines. With the development of growing interest in Medical Humanities, the importance of illness narratives has been renewed. Earlier, one particular 'medical perspective' or 'anatomical gaze' used to be considered standard in clinical practice. Diverting from the theory of the 'medical gaze' as the only reality, health professionals have recently developed their interests in evaluating the personal stories of illness as the patients who suffer from the disease are human beings and not just mere objects of treatment. Due to the unprecedented success of modern medicine and the commercialisation of the healthcare system over the last fifty years, the growth of medical humanities was necessitated to stand against the dehumanising tendencies of biomedical reductionism which put profits over patients. A continuous shift of attention towards machines rather than patients only “attends to pain but not suffering and to disease but not illness” (Cole, Carlin, and Carson, 2015, p. 16). Arthur Kleinman has identified the difference between ‘disease’ and ‘illness’. ‘Disease’ includes the pains and symptoms of the physical body but ‘illness’ also includes the sufferings and subjective experiences of the lived body. The term ‘illness’ includes the patient’s and family member’s perception of the disease, its symptoms, and disability (Kleinman, 1989, p. 3). A more nuanced understanding of illness through illness narratives has become a new challenge for medical humanities as its scope, role, and future have always been a matter of debate and discussion.

The first shift of attention from biomedical reductionism to medical humanism occurred around the 1960s and 1970s. Looking back on the history of medical bioethics, the physician-reformer Edmund Pellegrino introduced it as a ‘salvation theme’ meant to absolve modern medicine of its ‘sins’ (Cole, Carlin, and Carson, 2015, p. 20). Pellegrino included the valuable specification of the problems of modern medicine under the rubric of dehumanisation, which needs to be addressed in ethical studies: “overspecialization; technical; over professionalization; insensitivity to personal and sociocultural values; too narrow a construal of the doctor’s role; too much science; not enough liberal arts; not enough behavioural science; too much economic incentive; a ‘trade school’ mentality; insensitivity to the poor and socially disadvantaged; overmedicalization of everyday life; inhumane treatment of medical students; overwork by house staff; deficiencies in verbal and nonverbal communication" (Pellegrino, 1978, p. 9). Along with his important contribution to Bioethics, Pellegrino has also established the need to inculcate critical self-examination in the field of medical humanities (Cole, Carlin, and Carson, 2015, p. 21). By following Pellegrino's footsteps, the humanities could confer "those attitudes which distinguish the educated from the medically trained (Professional)" (Pellegrino, 1978, p. 3). Therefore, a study of bioethics always necessitates an integration of "knowledge, compassion, and action in the world" for humanistic education in medicine (Cole, Carlin, and Carson, 2015, p. 21). In recent times, healthcare ethics also talks about the problem of hierarchy as doctors are more privileged over other health professionals including nurses, and dentists (p. 22). Thus, the overprofessionalisation and hierarchical gap lead to a significant amount of epistemological knowledge gap between the patients and healthcare professionals which needs to be overcome.

Over the recent few years, there has been a significant growth in scholarly explorations into epistemic injustice to develop an understanding of the negative social experiences of ill persons within or beyond the clinical world (Kidd & Carel, 2019, p. 152; Kidd & Carel, 2017; Blease et al., 2017; Carel & Kidd, 2014; Carel & Györffy, 2014). In conventional healthcare settings, professionals often downgrade patients' testimonies, subjective feelings, experiences, and existential crises because of the strict professionalisation of interaction and lack of time (Kidd & Carel, 2017), thus causing the experience of epistemic injustice in patients. Epistemic injustice is generally defined as "a wrong done to someone specifically in their capacity as a knower" to mark negative stereotyping and prejudice against certain racial and sexual groups (Fricker, 2007, p. 1). Within the healthcare system, such experiences of injustice cause deep harm to the patients' epistemic capacities which are integral to their rationality, identity, agency, and dignity (Kidd & Carel, 2017, p. 175). As health professionals often enjoy credibility excess due to their professional training, grasp of medical jargon, and expertise in their fields, "patients' testimonies are often dismissed as irrelevant, confused, too emotional, unhelpful, or time-consuming" and thus they suffer from testimonial injustice (Carel & Kidd, 2014, p. 530). However, such subjective standpoints of illness are also important to develop a holistic understanding of breast cancer as opposed to merely the objective knowledge of healthcare professionals. Like other chronically ill persons, breast cancer patients are also subjected to ethnocentric epistemic injustice (Kidd & Carel, 2019, p. 158; Younas, 2021). However, discourses concerning epistemic injustice in breast cancer have not been sufficiently addressed even though various aspects of it are included in research and practice. By drawing more serious attention to this, we may lead ourselves to create better sensitive healthcare for all breast cancer patients in future. Therefore, patient and active listening along with practicing empathy should be a benevolent practice while treating patients inside the hospital settings. As patients build up their stories based on the holistic experiences of body and mind, it fills the gap in doctors' interpretation of objective knowledge of human anatomy, thereby suggesting that doctors practice 'open-mindedness' as an anti-prejudicial virtue so that patients' stories are not only encouraged to be told but can be believed (Kwong, 2015, p. 340). When the sufferers create the testimonies, the readers become more informed about the epistemic injustice in healthcare and the subjectivity towards an illness. Thus, healthcare can gradually pave the way for the realisation of the capabilities of patients through a positive nonjudgemental approach by ensuring epistemic justice to the ill.

The previously formed field “Medical Humanities” has now transformed into “Health Humanities” to include many more dimensions as it has become a field that cannot be called a discipline. Earlier, Medical Humanities mostly included the standpoints of physicians and healthcare professionals. The major movement towards being more vibrant, pluralistic, and inclusive facilitates the field to grow in a manner to borrow eventually from many disciplines like history, literature, anthropology, sociology, philosophy, religion, and other arts and sciences (Cole, Carlin, & Carson, 2015, p. 21). Therefore, medical humanities have become a new field that is multidisciplinary, interdisciplinary, and even post-disciplinary too (Atkinson et al., 2015, p. 72; Chambers, 2009; Evans & Macnaughton, 2004; Lewis, 1998). By holding the hands of Paul Crawford and other colleagues, the health humanities takes the place of medical humanities as a field to include all the other standpoints of illness besides doctors’, for instance, of patients, caregivers, nurses, and allied professionals (Atkinson et al., 2015, p. 72). Even after having varied and multidimensional focus inside the field, what unites the health humanities scholars is their critical engagement with the understanding of the subjective experience of illness as it becomes distinct from the biomedical attribution of disease (p. 72). The courses in Medical Humanities were first introduced in the curriculum of the University of Florida, then in the University of Texas followed by many others, and now 80% of the medical schools in the United States offer courses in the Humanities (Van den Berg, 2015, p. 628). In India, like many other developing countries, there are a few remarkable initiatives to include humanities for the betterment of healthcare. For instance, Dr. Satendra Singh and colleagues first took the initiative at the University College of Medical Sciences, New Delhi, to introduce medical humanities into the curriculum. Thereafter, there is also a growing interest at the Seth Gordhandas Sunderdas Medical College in Mumbai and at the PSG Institute of Medical Sciences and Research in Coimbatore among various institutions (Shankar, 2016, p. 166). As India already has a rich tradition of storytelling, special attention is required to be given to encouraging stories of illness as an important part of medical education in India too like the Western countries (Shankar, 2016, p. 167). However, there is still not enough growth in illness stories among Indian patients, caregivers, and professionals as compared to their Western counterparts.

1.4 History and Function of Breast Cancer Literature

Like other illness narratives, breast cancer narratives have also seen a sudden rise in number around the 1980s through their journey from private to public. Earlier it had been a personal phenomenon to share one’s illness stories mostly in the form of diaries and personal letters. As per Hawkins, any chronic illness narratives in book-length form were quite uncommon before 1950 and were rarely found before 1900 (1993, p. 3). As numerous organisations have gradually started spreading awareness, the privacy and silence involving breast cancer have broken and have translated into narrating and sharing stories. However, the feminist movements of the 1960s and 1970s have played an important role in visualising the generous number of literary representations of breast cancer. In the early 1970s, the women’s movement addressed issues about female autonomy, body, health, and medicine, thus facilitating breast cancer's visualisation process. Around the same time, the famous diagnosis of the then First

Lady of the USA Betty Ford, and the then Second Lady Happy Rockefeller in 1974 provided the instant recognition of breast cancer among Americans. With the popularisation of the disease, the narratives of breast cancer have become popular to study women’s cancer experiences. The earliest instances of breast cancer narratives are *Mastectomy Letters* (1811) by Frances Burney and *The Diary of Alice James* (1894) by Alice James, although they do not receive critical attention until the visualisation of breast cancer (Kasthuri & Venkatesan, 2017). Women’s breast cancer narratives provide the readers with various scopes to study the lived experiences of women confronting a life-threatening disease and changing reality. For instance, Burney has elaborately discussed her own radical mastectomy experience without anaesthesia and thus criticises the medical practices for reducing her to a mere object of treatment. Similarly, Alice James shares her breast cancer experience by considering it a ‘vindication’, and thus it has become “a significant precursor for contemporary women writing of the illness” (Couser, 1997, p. 78). After these two pioneering works by Burney and James, there are many iconic breast cancer narratives, like George Crile’s *What Women Should Know About the Breast Cancer Controversy* (1973), Rose Kushner’s *Breast Cancer: A Personal History and An Investigative Report* (1975), Betty Rollin’s *Fist, You Cry* (1976), Susan Sontag’s *Illness as Metaphor* (1978), and Audre Lorde’s *The Cancer Journals* (1980) (Kasthuri & Venkatesan, 2017). Most breast cancer narratives generally have a public mission to fulfil a political agenda, as it is different from many other narratives of illness. As per Couser, the hidden political motive behind breast cancer narratives is “to expose to public view a deadly disease that warrants individual wariness, public concern, and aggressive research into causes, prevention, and treatment” (Couser, 1997, p. 37). Although breast cancer survivors or non-survivors who decide to narrate their story are primarily “self-concerned during their illnesses, in the act of writing they seek to enhance others' chances of survival and to support them by sharing their experiences” (Couser, 1997, p. 37). Through sharing their stories, they not only “wish to focus public attention and resources on their disease in the hope of minimizing its potency” but also increase the chances of survival in others through sharing possible coping mechanisms (Couser, 1997, p. 37). Similarly, Diane Price Herndl has marked the importance of Lorde’s *The Cancer Journals* as it has not only broken the silence about breast cancer but also encouraged other women to transform the language from silence into action (Herndl, 2006, p. 221). She has also mentioned that the writing itself is both a political and an ethical act: “Not only should one write about one’s experience of cancer, but doing so is a political act, and doing so correctly is an ethical act” (p. 221). Thus, following Lorde, many other writers attempt to bring dimensions of race, class, sexual orientation, and gender to the discussions on breast cancer.

Although there is a sudden growth in the number of Anglo-American Breast Cancer narratives, there is still a need to voice other marginalised classes, races, and nationalities who are non-white or poor and do not “have the literacy, leisure, and inclination to write their stories-and the contacts to get them published” (Couser, 1997, p. 38). Every culture perceives breast cancer differently because of their different education and awareness. For instance, breast cancer in India is often still more stigmatised than in American culture. Indian women’s cancer narrative or memoir is therefore still a less-developed genre as it includes only a few works like Minakshi Chaudhry’s *Sunshine* (2011), Anagha Morje Ghosh’s *Face to Face with Cancer*

(2012), Neelam Kumar’s *To Cancer, with Love* (2015), Monisha Koirala’s *Healed* (2018), Lisa Ray’s *Close to the Bone* (2019), and Shormistha Mukherjee’s *Cancer, You Picked the Wrong Girl* (2021). The literary representations of breast cancer are also fewer in number because of the predominant silence in Indian women’s cancer narratives as compared to their Western counterparts. Most autobiographical texts dealing with breast cancer as a life-changing event generally come from an Anglo-American background. Therefore, American breast cancer memoirs have long overlooked the stage of breaking the silence regarding breast cancer as it used to be considered the initial stage. Currently, American breast cancer memoirs address the issues of post-awareness societies, breast cancer optimism, reconstruction as an informed choice, sexism inherent in the pink campaigns, going beyond ‘look good’ campaigns, and ethics beyond mass screening (DeShazer, 2013, p. 49; 116; 147). Breast cancer narratives are not only available in the form of published and printed autobiographical texts but also are found in many other mediums like breast cancer blogs, newspapers, magazines, and even supporting group websites. Some instances of popular blogs and websites are Breast Cancer Action, The Breast Cancer Fund, Breastlink, Breast Pink, Cancer Bitch, Komenwatch, BC Mets, and Cancer Diaries (DeShazer, 2013, pp. 205-6). Such platforms spread awareness among women for breast examination at a certain age and help to create a community among all such cancer patients by following others’ experiences. Breast cancer narratives have brought certain awareness from many different perspectives, particularly with the advent of various new disciplines or fields like medical humanities and narrative medicine.

1.5 Emergence of Narrative Medicine

Our understanding of personal narratives of illness experiences constitutes a major amount of attention in the medical humanities (Atkinson et al., 2014, p. 77). Especially, the personal narratives of the lived experiences of patients, caregivers, and others have made a significant contribution to Narrative Medicine as it considers honouring stories. Rita Charon is the first to use the term "Narrative Medicine" to introduce a different subfield inside medical humanities that has been mainly initiated from the major concern to improve medical training (Charon, 2006). The practice of reading and writing narrative texts addresses various important issues in medicine, including "multicultural medicine, access to care, death and dying, pain, empathy, medical mistakes, and physician impairment" as they are otherwise ignored in scientific and biomedical approaches and thus supplement other components of evidence-based medicine (Van Den Berg, 2015, p. 627). As per Charon, active engagement in Narrative medicine can help physicians develop narrative competence for bridging the gap that separates physicians from patients, themselves, colleagues, and society (Charon, 2001, p. 1897). Narrative medicine originally aimed to find the necessity of developing a more nuanced understanding of patients' experiences by healthcare professionals. According to Sarah Pett, the pedagogical approach of Narrative medicine includes the close reading of illness narratives and creative writing, and both these practices are intended to equip medical students with narrative competence including the skills of observation, analysis, empathy, and self-reflection (Pett, 2014, p. 35). Narrative medicine emphasises the value of interrelated and competing narratives of patients, physicians, caregivers, and others to grow a better understanding of the disease process and medicine – diagnosis, treatment, and prognosis (Van Den Berg, 2015, p. 628). Therefore, a study of narrative medicine brings fresh opportunities for respectful, empathic, and nourishing medical care (Charon, 2001, p. 1897). In recent times, narrative training has become more popular under the rubric of Narrative medicine, which involves “close reading, attentive listening, and reflective writing” to practice inclusiveness inside healthcare (Crawford, Brown & Charise, 2020, p. 20). Narrative training is required because scholars have established how it is important to develop narrative competence to effectively interpret, understand, and reflect on people’s bonding with their illness, their lived experiences, and their meaning-making process (Crawford et al., 2015, p. 53; Frank, 1995). When a person is ill or a near one falls sick, then that person generally relocates herself inside the story to understand the unexpected turn of events of her life and takes the help of others to discover the newly-found self (Cole, Carlin, & Carson, 2015, p. 289). It is difficult to draw meaning out of the patients’ stories because meaning is “not latent in patients’ symptoms waiting to be manifest and deciphered” by the doctors as it is located contextually and articulated metaphorically in the form of storytelling (Cole, Carlin, & Carson, 2015, p. 289). “Following the story” always helps both the patients and doctors to have a holistic understanding of illness as they both act as “interpreters of the illness and joint authors of the illness narrative” (p. 289).

1.6 Review of Literature

Several studies have established breast cancer as the most disturbing disease for women as they lose the most important organ of their body which constructs their womanliness (Mol, 2022; Bu et al., 2022, Trindade et al., 2018). Therefore, breast cancer narratives feature the loss of one/two breast/s in women, lamentation on the changing physique, loss of hair, change in weight, fertility, energy, and sexuality as breast cancer elevate the feelings of isolation, helplessness, and marginalisation (Mol, 2022, p. 1). Reshna Mol in her thesis “Redefining Selves: Women’s Breast Cancer Narratives” has studied the changing self, and identity crisis along with the bodily changes in breast cancer narratives to understand the feminist point of view on this matter by using the theoretical concepts of Audre Lorde, Tasha N. Dubriwny, Elaine Scarry, and Kelly Oliver (Mol, 2022, p. 1). Such studies have established that medical memoirs should be studied with equal importance as case histories of illness or physicians’ accounts that are mostly taken seriously inside healthcare. Several patterns of illness narratives are found in various major studies. The sufferers do not make up the stories themselves but they subscribe to the already provided “narrative templates” a society makes available to them (Frank, 2005). Arthur Frank in his *The Wounded Storyteller* has found three major types of illness narratives: a) Restitution narratives, b) Chaos narratives, and c) Quest narratives. In the Restitution narratives, the narrators always go back and forth in their states of health in terms of the plots of narratives: “Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again” (Frank, 1995, p. 77). The Chaos narratives involve the plot in such a manner that all the life events are contingent and nothing is in control: Life is ‘never getting better’ (Frank, 1995, p. 97). The last and most commonly preferred category is the Quest narrative, where the life events are narrated so that the illness itself looks like a journey (Frank, 1995, p. 115). The previously discussed three narrative templates or categories are suitable for particular locations and particular times when it was invented (Frank, 2005). Even though every narrative follows a pre-existing cultural template, it reflects the narrator’s cultural understanding while providing an insight into their illness. By studying breast cancer narratives in terms of Frank’s categorization, an understanding has been developed of how breast cancer patients often perceive their illness, whether in terms of chaos or a journey (Thomas MacLean, 2004).

Breast cancer is one such disease that involves many mutilating treatments that are disturbing to feminine identity, body image, and sexuality. The socio-cultural understanding of women’s breasts also plays a major role in the perception of breast cancer:

> Woman is a natural territory; her breasts belong to others – her husband, her lover, baby. It‘s hard to imagine a woman‘s breasts as her own, from her own point of view, to imagine their value apart from measurement and exchange (Young, 2005, p. 80).

In almost every culture, women’s breasts are considered the most visible signs of the woman’s femininity and the epitome of her sexuality. According to Young, women’s breasts are never thought of as their own in a male-dominated society and therefore woman-centred breast experience is a construction (Young, 2005, p. 80). Marilyn Yalom (1997) in her book *A History of the Breast* has covered the different perspectives towards female breasts categorically, including ‘the sacred breast’, ‘the erotic breast’, ‘the domestic breast’, ‘the political breast’, ‘the psychological breast’, ‘the commercialized breast’, ‘the medical breast’, ‘the liberated breast’, and ‘the breast in crisis’ (pp. 3-5). As a pioneering feminist scholar, Yalom has captured a breast discourse spanning almost twenty-five years to cover the perception of breasts in religion, politics, psychology, society, and the arts. Over the ages, women’s breasts are portrayed as good to bad, sacred to erotic, life-giving to life-destroying, depending on religious, political, media, and medical agendas. Women's breastlessness leads to a difficult body-image crisis because it disrupts their feminine identity as breasts are constructed as symbols of their ideal sexuality, and thereafter, disrupts their perfect motherhood because they become incapable of breastfeeding. When women's breasts are diseased with cancer, then they are amputated, and thus breast cancer often becomes the leading cause of breastlessness in women (pp. 210-11). As breast milk used to be perceived as a purified form of menstrual blood, Hippocrates, the father of Western medicine, has associated the origin of breast cancer with 'the cessation of menses' (p. 207). Similarly, as menopause used to be believed earlier as the primary cause of cancer in women's breasts, the regular changes in women's bodies were feared. Along with this, the fear of breast loss in women is greatly associated with the fear of losing social roles such as motherhood, femininity, and sexuality (Francesco & Orellana, 2020, p. 5).

Langellier and Sullivan in their important work "Breast Talk in Breast Cancer Narratives" have emphasised the importance of talking about this altering image or identity and they have categorised breasts into four categories: the medicalised breast, the functional breast, the gendered breast, and the sexualised breast. Their study has also mentioned that the detached and highly abstracted language creates an even more difficult communication barrier between doctors and patients (1998, p. 80). Women face the challenge of narrating their disfigured body image associated with medicalised breasts, the daily functionalities and nurturing capabilities of the functionalised breast, gendered feelings and consciousness related to the cultural meaning of breast, and distorted selfhood experiences associated with sexualised breasts. The experience related to the physical breasts of such women affected with breast cancer not only includes their subjective experiences, but also initiates a discussion about the different dimensions of breasts including body image, femininity, and sexuality. This study has also hinted at the embarrassment women suffer from after the breast cancer diagnosis. It has thoroughly studied how women's changing breasts, bodies, and selves are communicated through their language.

Research establishes that women's psychological health is highly affected because of the shame associated with body image impairment (Trinidade et al., 2018). The feelings of uselessness, unattractiveness, and distorted self-perception create serious problems like hindrance of psychological flexibility, cognitive fusion, and decreased quality of life among women (Trinidade et al., 2018, p. 891). Although breast cancer is considered the most curable disease if detected in the early stage, the need to address the informational and emotional requirements among breast cancer patients is well established through many recent studies (Vivar & McQueen, 2005, p. 520). Due to the sick role assigned to the patients, the whole truth about diagnosis and treatment is most often not shared with breast cancer patients which even leads to othering (Klawiter, 2008, p. 36). Following Talcott Parsons' (1951) model, Klawiter points out that individuals with sixty-six dangerous signals of breast cancer are labelled as high-risk patients and thus such individuals are marked with the sick role (2008, p. xxvii). Their sick identity, therefore, supports the doctor's authority and dominance on one side, demands the patients' obedience, and imposes ignorance on the other.

During the advent of second-wave feminism, the patient's informed consent, different surgical methods, adjuvant therapies, and patient care initiatives are introduced, redefining the roles and duties of physicians and patients in cancer care (p. xxviii). The paradigm shift in breast cancer culture and social activism has a major impact on the shifting focus in breast cancer narratives. Breast cancer activism is a complex phenomenon as it has three important dimensions. Firstly, it promotes early diagnosis and screening as preventive measures symbolised by the pink ribbon and promotes cheerful pictures of breast cancer survivorship (p. xxvii). Secondly, it talks about the overall empowerment of women affected by breast cancer emphasising the need for informational and emotional caring. This positive culture of empowerment not only provides women with a voice and power to nurture their self/identity but also influences cancer research treatments by developing a living cancer identity (p. xxx). Thirdly, it also puts cancer in its ecological context to engage in cancer-environmental studies and investigate the possible ways to reduce carcinogen exposure (p. xxx). Due to this multi-faceted focus of breast cancer activism, less attention has been paid to women’s personal fear, inner crisis, shame, and psychological distress which have the potential to hinder their personal help-seeking behaviour, treatment process, and receiving care. The narratives about cancer both celebrate the confidence of the narrators in their survival and explicitly criticise the denial of death in American culture by sharing their experiences with death anxiety (Couser, 1997, p. 65). Western culture generally defines progress in terms of material success and often ignores "death, illness, or ageing as part of life" (Baena, 2020, p. 372). Mary K. Dehazer, in her chapter, "Bodies, Witness, Mourning: Reading Breast Cancer Autothanatography," has emphasised the importance of studying grief, anger, loss, and death in public narratives of breast cancer (DeShazer, 2013, p. 177).

Fear, anxiety, depression, and psychological distress are considered to be various forms of emotional reactions observed commonly in any breast cancer patient bearing the burden of the ‘sick role’ (Holmberg, 2014, p. 175; González-Fernández et al., 2017, p. 75). It is necessary to study breast cancer patients’ understanding of illness through emotional reactions like fear, anxiety, and shame because it is an important part of care and cure. Finding the lumps in the breast is not the only reason for such challenging emotions but the routinised procedure of the breast examination, treatment, and chemotherapy also create such emotions. The woman’s vulnerability can also be caused when “her precious breast fruit has become a site of possible invasion” or an object of medical treatment and medical gaze (Wear, 1993, p. 85). Delese Wear in her “Your breasts/ sliced off: Literary Images of Breast Cancer” has studied many such metaphors of “denial and fear”, “sadness and pain”, “shame through others’ eyes”, and “transcendence” based on twentieth-century North-American literature. Her study has also reflected how women feel extreme levels of fear and anxiety because of facing a potentially fatal disease, and of losing a potential part of their body deeply associated with their sexuality/ femininity/ self (Wear, 1993, p. 82). Besides recognising women’s feelings of sadness, pain, and shame; research has acknowledged the need to cope with these challenging emotions through self-acceptance, hope, transcendence, and strength (p. 95). There is “no absolute diagnosis, no single agreed-upon text, but only the interpretation” of every single patient which they come up with in every single situation (p. 98). Thus, it is necessary to delve deeper into individuals' emotions, interpretations, and coping mechanisms through their narratives, as it is otherwise impossible to understand in formal healthcare. In recent times, hospitals first showcase their improved technologies instead of their physicians’ sense of compassion and humanity

(Nayar, 2009, p. 24). Due to this increasing stress given to the technologies to analyse problems and crises of the patients, the emotions and psychological distress in patients are undervalued inside formal healthcare. Therefore, humanities have gradually been introduced as a discipline to emphasise the emotional responses, lived experiences, and life stories of patients:

> The foundation of healthcare practice, across all disciplines, should be based on hearing, respecting, valuing and responding to people's experiences, interpretations, relationships, priorities, emotions and life stories. (Crawford et al., 2015, p. 53)

Looking at the importance of illness stories, Dorothy Broom in her article "Reading Breast Cancer" has marked that mostly the sociocultural fears of death, disease, sexuality, and femininity shape the breast cancer stories. Breast cancer stories are specifically studied to understand women-specific experiences: "If the breast is ambiguous, so is its absence" (Broom, 2001, p. 259). Due to excessive awareness in the developed countries in the United States and the UK, women are forced to wear a prosthetic breast, have reconstruction surgery, and wear a brave face along with wigs or scarves to hide baldness or body marks, so that they can continue with the public optimism (pp. 259-260).

The feminist and breast cancer activist Audre Lorde opposed this tyrannic cheerfulness of breast cancer optimism as she proclaimed that breast cancer is not a "cosmetic problem" (Lorde, 1980, p. 24). In American culture, breast cancer is a disease that is associated with many conflicting and complex knowledge (Potts, 2000, p. 15). Maren

Klawiter in her book *The Biopolitics of Breast Cancer*, has centred her argument on the relation between power and bodies because women's bodies are not only related to power politics but are also signifiers of health, illness, risk, and disability, (ab)normality, beauty, death, and disease (Klawiter, 2008, p. xxx). Klawiter has mainly relied on the idea of 'technologies of the body' to convey the story of the evolution of the breast cancer movement in the twentieth century and its ramifications for creating new perspectives, themes, social activism, and solidarities (2008, p. xxvi). The knowledge about breast cancer and women's understanding and experiences about it are drawn from multiple resources. The dominance of the 'medical gaze' as the producer of biomedical knowledge about the body and its diseases undervalues the subjective production of knowledge by sufferers (Potts, 2000, p. 21).

Earlier, in the eighteenth century, breast cancer used to be considered nightmarish among women as it was considered the most common but the most dangerous (Kaartinen, 2015, p. 1). Over time, the perspectives on breast cancer have changed along with the improvement in healthcare scenarios and the invention of several medical technologies in the twenty-first century. Mary K DeShazer in her book *Mammographies* has observed that the recent post-millennial Breast Cancer narratives address many important issues that were previously neglected: shifting politics of prosthesis and reconstruction, links between cancer and environmental carcinogens, ethics and efficacy of mastectomy, and genetic testing (2013, p. 1). However, the biomedical knowledge of breast cancer in the eighteenth century was close to layman's discourse because of the less development in technical healthcare facilities (Kaartinen, 2015, p. 2). Recently, with the development of biomedical knowledge, the gap between layman’s knowledge and scientific knowledge has widened. Therefore, the growth in writing and reading breast cancer stories was necessitated to overcome the gap between subjective and objective knowledge, and to significantly emphasise women’s subjective feelings about the altered reality of breast cancer. “By now there is surely a published breast cancer autobiography by someone from every western nation and geographical region, any occupation, every religious and political persuasion, and claiming the range of prognosis from complete cure to imminent death” (Broom, 2001, p. 261).

Two important incidents have brought a revolution in looking at breast cancer narratives: “Information is power” as the implicit slogan of the 1980's Women’s Health Movement, and the discovery of the marker genes in BRCA1 in 1994 and BRCA2 in 1995. The first incidence assumes that empowered women have more control over their lives and bodies through sharing information (Potts, 2000, p. 7). With the identification of genes, the narratives of women who are cancer-free but have high risk become also popular which are known as BRCA or ‘previvor’ narratives (DeShazer, 2013, p. 2). DeShazer has also brought to attention both photographic and literary narratives because they record the visual and vicarious experiences of the same emotion among readers through two different types of media portrayals. Graphic narratives and blogs are the recent forms of cancer memoirs that show a new aesthetic emerging around self-representation (DeShazer, 2013, p. 9). The purpose of all these different forms of breast cancer stories is not only the standardisation of recounting the lived experiences but also the widening of the perspective by learning from others’ experiences (Potts, 2000, p. 100). Therefore, more studies are needed to understand the subtle changes in emotion shared by breast cancer patients: both survivors and non-survivors. The politics of perceiving the patients as ‘survivors’ under the optimistic culture of breast cancer has been mentioned by Samantha King in *Pink Ribbons, Inc.: Breast Cancer and the Politics of Philanthropy* (2006). In the pink ribbon culture, the survivors’ fortitude and hope, together with research resources are the finest weapons against illness (King, 2006, p. x). Narratives are not only the by-products of their personal feelings but also of their respective culture.

As the survivors’ stories are given more importance because of breast cancer awareness and optimistic culture, the non-survivors' emotions are not encouraged to be recorded (King, 2006). Scholarly work based on the Pulitzer Prize-winning book *The Undying* (by Boyer) establishes that death in breast cancer is generally demeaned in the pink ribbon culture as it only focuses on champion survivors (Iwai, 2021, p. 802). Rosalia Baena in her book chapter “When Time Stops”, has studied the patients’ coping strategies against fear of death, and the process of dying. This research is based on three memoirs Paul Kalanith’s *When Breath Becomes Air*, Nina Riggs’ *The Bright Hour,* and Jenny Disky’s *In Gratitude* (Baena, 2020). Most of these narrators have approached life in a very optimistic and even accepted reality in humorous ways. Showing gratitude, reading literature, and reflecting on Nature as a source of positive energy are some of the important coping strategies (Baena, 2020, pp. 375-6). Research has shown the importance of self-creation amidst the process of self-extinction because it also engages readers with the process both ethically and experientially (p. 382). The scholarly works have also established the significance of humour and comic relief in the painful, tragic drama of cancer. The use of humour is very frequently recognised as an important coping strategy because it provides cancer patients with a “Nietzschean moment of joyful forgetting” and transcendence from grief (Willett & Willett, 2020, p. 535). Under the broad term of humour, comic denials or diversions, bargaining, truth-telling through ridicule, unmasking, authenticity, empathy, and a comic vision of new identities and norms are some of the important techniques used by Tig Notaro and Hannah Gadsby in their narratives (pp. 540-6).

Along with this, the breast cancer narrative domain is mostly overflooded with voices of Western, heterosexual, and white women (Broom, 2001; DeShazer, 2013). Therefore, there is still a major gap in studying the similarities and differences in narrating challenging emotions like fear, anxiety, guilt, and shame associated with breast cancer across different cultures. So, a comparative study between Indian and American breast cancer narratives will address this gap. There are only a few studies addressing breast cancer patients’ coping mechanisms, which involve mainly some passive coping strategies like withdrawing from stressors (Dubey & Kumari, 2017, p. 12). Three patterns of coping strategies are generally observed among Indian individuals: (a) emotion-oriented strategy, (b) avoidance-oriented strategy, and (c) task-oriented strategy (Singh, 2011). Owing to the several cheerful optimistic cultures of breast cancer, social activism, biopolitics, and feminism, women’s narratives are studied from different ethical, environmental, and political perspectives (Potts, 2000; Klawiter, 2008; DeShazer, 2013). Overcoming this politics of representation and the research gap in understanding the challenging emotions, requires studying the breast cancer narratives of different socio-cultural groups to understand the similarities and differences in challenges they face after breast cancer diagnosis. Similarly, there is a necessity to formulate a common possible framework for coping with the challenging emotions after breast cancer diagnosis.

1.7 Objectives **and Research Questions**

1.7.1 Objectives

a) To explore, analyse, and critique the different dimensions of fear and shame as recorded in their personal narratives by the select Indian and American breast cancer memoirists spanning 2011 – 2021.

b) To develop an understanding of fear and shame as two of the most challenging manifestations of biographical disruption, which occurred in the lives of breast cancer patients from two different cultural backgrounds.

c) To explore the differences present in the culture of silence and shame existing both in Indian and American contexts.

d) To understand the universality of emotions even after the huge differences in culture, beliefs, economy, and healthcare facilities between Indian and American contexts. To find out a possible connection between two different cultures of breast cancer and to know if patients can build a community of breast cancer patients through locating similar feelings.

e) To understand both the similarities and differences in the coping mechanisms on an individual level even though all the patients pass through the similar shocking news of diagnosis and the challenging treatment procedures beyond that.

f) To find out whether the breast cancer-affected women possibly create a community for themselves through their coping strategies to overcome the tormenting effect of breast cancer as a biographical disruption and the sharing of their emotions.

1.7.2 Research Questions

To fulfil the objectives of the research, the following research questions are addressed in the current study:

a) How do both Indian and American breast cancer patients share two significant challenging emotions—fear and shame—that are universally present? In what aspects are they similar and different?

b) How do differences in cultures, politics, and healthcare facilities affect the feelings of producing difficult emotions like fear or shame? How do they build a community for themselves despite belonging to different cultures, different occupations, and different strata of society?

c) How is fear equally challenging for both Indian and American patients? How are their expressions of fear and metaphors used for death anxiety different in both Indian and American contexts?

d) How do Indian patients face more challenges in expressing shame related to breast cancer than American patients? How does breast talk need to be normalised in the Indian context to pave the way for writing more breast cancer memoirs?

e) How do breast cancer patients try to explore new identities by accepting the new normal and finding a way for autobiographical reconstruction?

f) How do women in the post-millennial era find a way to survive through these two overpowering emotions to regain control of their lives? What are the major and minor strategies found in postmillennial breast cancer memoirs? How can the coping mechanisms used by patients be helpful to others struggling with similar challenges?

1.8 Materials and Methods

The primary texts chosen for this thesis are three Indian breast cancer memoirs *Sunshine: My Encounter with Cancer* (2011), *To Cancer, with Love: My Journey of Joy* (2015)*, Cancer, You Picked the Wrong Girl: A True Story* (2021)*, and* three American breast Cancer memoirs *I'm Just a Person: My Year of Death, Cancer and Epiphany* (2016), *The Bright Hour: A Memoir* (2017), and *The Undying: A Meditation on Modern Illness* (2021).

1.8.1 Indian Breast Cancer Memoirs:

1. Minakshi Chaudhry's *Sunshine* (2011): As an Indian author and former journalist from Himachal Pradesh, Minakshi has recorded the darkness of her life openly in her positive memoir *Sunshine* (2011) as the title itself is entangled with the ray of hope. Aided by her extremely caring husband, Rakesh, along with other family members, she has coped with numerous obstacles and gained a new approach to life.
2. Neelam Kumar's *To Cancer, with Love* (2015): Neelam Kumar is a Mumbai-based bestseller author and motivational coach who has adopted a completely new perception towards life after her two times' survival with breast cancer. This entertaining but profound memoir by Neelam Kumar records her courage and humour in battling with physical and psychological trauma. Finding all possible sad literature available on cancer, she set her target to write cheerful motivational content to present the realities of the cancer battle in a different manner.

3. Shormistha Mukherjee's *Cancer, You Picked the Wrong Girl* (2021): As a Mumbai-based entrepreneur, Shormistha Mukherjee has written her debut autobiography *Cancer, You Picked the Wrong Girl* (2021). With the constant support of her positive-looking doctors, husband Rakesh, best friend Oindrila, and others; Shormistha has narrated how her cancer journey has become partially comfortable. Through the memoir, she has adopted a challenging tone towards a life-altering disease like cancer. Her example is an ideal case of understanding the importance of empathy, and compassion in overcoming the battle of cancer.

1.8.2 American Breast Cancer Memoirs:

1. Tig Notaro's *I'm Just a Person* (2017): As America's one of the leading comic voices, Tig Notaro has captured her personal and professional journeys after her breast cancer diagnosis. Even before breast cancer, she had gone through two different challenges of life - hospitalisation with an intestinal disease called C-diff, and the unexpected death of her mother. She has parallelly recorded her experiences of bilateral breast cancer, break-up with her lesbian partners, a breakthrough in her career as a comedian, and her risking her life for fertilising eggs to give birth to a biological child.
2. Nina Riggs' *The Bright Hour* (2017): As a former teacher and established poet, Nina Riggs has recorded her painful lived experiences when her cancer was detected and her normal life as a mother of two young sons was shattered. She was a resident of New Carolina, who was diagnosed with breast cancer at the age of thirty-seven which got terminal within a year. Hence, it was barely two years between her cancer

detection and death that she completed writing the poignant and evocative memoir *The Bright Hour* (2017).

3. Anne Boyer's *The Undying* (2019): As an American poet and essayist, Anne Boyer has recorded her personal life as well as century-old women's struggle with breast cancer through her *The Undying*, a memoir on breast cancer (2019). As a single mother, she was already under financial and emotional pressure, and under this backdrop, she was suddenly diagnosed with aggressive triple-negative breast cancer at the age of forty-one. This memoir reaches beyond the traditional memoir with its structure, lyricism, and formal experimentation as it is intertwined with cultural criticism, literary analysis, mythology, and even history.

The three inclusion criteria applied while selecting the memoirs that define the core objective of this thesis are as follows:

a. The possibility of a comparative reading between two different cultures, India and America, is opened through the choice of texts. Along with this, the period chosen reflects the current growth in breast cancer memoirs across cultures and maintains uniformity in a common theme-based cross-cultural study.
b. All the memoirs selected for the analysis have been written by middle-class working women and thus they are financially independent. Minakshi Chaudhry is an NGO activist and writer, Neelam Kumar is a life coach and motivational speaker, and Shormistha Mukherjee is an entrepreneur. Similarly, Tig Notaro is a comedian, Nina Riggs is a poet and writer, and Anne Boyer is a professor and writer.
c. In the Indian genre, all three Indian patients' narratives represent the voices of middle-class, heterosexual, and married women who have physically survived the

disease. Neelam Kumar is one of the three who have survived breast cancer twice in her lifetime. Among the American memoirists, both Nina Riggs and Anne Boyer are heterosexual women with long married lives and are also mothers of kids. Tig Notaro is a lesbian woman who wants to be a mother even after her breast cancer diagnosis. Both Anne Boyer and Tig Notaro have survived the illness, but Nina Riggs is a non-survivor, although her struggle with the illness provides us with important insights.

1.8.3 Theoretical Framework:

The thesis is conceptualised based on two important theoretical strands – Biographical Disruption by Michael Bury, and the Coping Framework proposed by Richard Lazarus and Susan Folkman – which are used to formulate the whole argument of the thesis. Michael Bury's (1982) biographical disruption is an important concept for understanding the major breakdown of life after the detection of a life-altering disease. Along with this, the coping framework propounded by Lazarus and Folkman (1980, 1984, 1988, 1993, 1999) is used to understand the second section of the thesis, dealing with the important coping mechanisms used by breast cancer patients to overcome the problem.

First conceptualised by Bury (1982) in the context of a study based on rheumatoid arthritis patients, biographical disruption explains the emergence of "chronic illness as a major kind of disruptive experience" (Bury, 1982, p. 169). The idea is premised on an earlier concept of the 'critical situation' which talks about 'a set of circumstances which - for whatever reason- radically disrupt accustomed routines of daily life' (Giddens, 1979, p. 124). Bury has extended Giddens' (1979) concept to include the disruption to biographical continuity occurring on the onset of a chronic illness: "Illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury, 1982, p. 169). After Bury introduced the term, biographical disruption became a major concept in medical sociology (Locock & Ziebland, 2015). Though Bury first studied 'biographical disruption' in the context of rheumatoid arthritis, it was later studied in conjunction with many other chronic illnesses like diabetes, HIV, and breast cancer (Potter, 2023; Wells et al., 2023; Trusson et al., 2016; Liamputtong & Suwankhong, 2015). Chronic illness is one such occurrence that does not shock us once but disrupts the body, self, and resources, and it also occurs at multiple points in time because chronic illness is subject to ongoing contestation and development. Sometimes, a diagnosis may represent less of a biographical disruption and more of another trial to contend with—one that might be comparatively less challenging than other events to fill their everyday lives (Ciambrone, 2001). Engman (2019) has recently expanded the theoretical basis of the concept, proposing embodiment as a lens through which to view the experience of biographical disruption. In chronic illnesses like breast cancer, people generally witness major alterations to their body, self, and resources causing numerous disturbing emotions like fear, anxiety, shame, and anger (Liamputtong & Suwankhong, 2015, p. 1086).

Though the concept of biographical disruption is applied to a great variety of chronic illnesses, it has not been widely associated with breast cancer. Bury has identified three forms of biographical disruption, disruption to the normal way of human beings, including bodily performance and help-seeking behaviour, disruption to self or identity involving a change to the individual’s sense of self and position within society, and disruption to both material and social resources that people rely on for everyday life. The severe disruption of the body, self, and resources due to chronic illnesses causes an inner torment of the soul by degrading one’s position as a diseased body or self in society. Multiple changes are brought in the life of the individual due to chronic circumstances which include the rise of evidence-based medicine and shared decision-making and therefore create a different practical and symbolic application of the diagnosis of disease. For Bell et al. (2016), illness experiences may be best understood through the idea of ‘biographical oscillation,’ and chronic illness is “usefully reframed as one of many ‘biographical oscillations’ encountered in the life course that re-route us between continually shifting, often ‘messy’ and unanticipated life trajectories” (Bell et al., 2016, p. 184). By using the concept of ‘biographical disruption’, the next two chapters will study the experience of fear and shame as important manifestations of biographical disruption in the selected Indian and American women’s breast cancer memoirs to understand the threatening impact of the deadly disease on a patient’s body and self to understand the effects of illness and treatment on their mind. Further, using this theoretical framework by Michael Bury and others, the present thesis will go beyond the initial analysis of breast cancer as a major form of biographical disruption, to explore the existence of a ‘turning point’ (Strauss, 2007; Pranka, 2018, p. 2) and a ‘fateful moment’ (Giddens, 1991; Pranka, 2018; p. 2), which has the potential to generate epiphanic moments of life leading a person to rediscover the self and reconstruct the identity autobiographically (Potter, 2023: 19).

Using the concepts of biographical disruption as proposed by Michael Bury and later followed by many others including Bell et al., Engman, Strauss, Pranka, and others, the second and third chapters are used to understand fear and shame as a manifestation of biographical disruption. The chapter on fear and anxiety consists of additional theoretical frameworks to investigate the different dimensions of fear particularly contextualising it in the breast cancer scenario. Similarly, the next chapter on shame and crisis of self consists of an additional theoretical framework to understand the connection between biographical disruption and shame and how it creates bodily shame and a crisis of self among breast cancer patients.

The patients use several coping strategies to overcome the devastating effects of biographical disruption and to improve their quality of life. The most popular understanding of coping has been developed by Lazarus and Folkman which talks about three levels of coping mechanism, coping as a cognitive mechanism (e.g., how one thinks about the diagnosis), coping as a behavioural mechanism (e.g., what one does about it), and efforts to lessen and control the impact of a stressor (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Folkaman & Lazarus, 1988). The first two steps are generally referred to as 'primary appraisals' and 'secondary appraisals' as they help to evaluate the current situation, and thereafter involve the consideration of what to do about it. The third step has two important subcomponents: taking positive action to help solve the problem (e.g., gathering knowledge and seeking tangible support) and unconsciously or consciously working to address the emotional distress associated with the problem (expressing distress, acceptance, avoidance, emotional support-seeking). Lazarus has also discussed two types of coping: Problem-focused coping and emotion-focused coping. In problem-focused coping, certain behavioural strategies are adapted to solve the problem or situation. In emotion-focused coping, certain behaviour is adapted to change the emotional reactions to the problem or situation (Lazarus, 1999).

As coping is generally considered an ongoing behavioural effort to manage specific external or internal demands, it only comes up from the sudden hindrances in the life of an individual (Lazarus, 1993). Developing a ‘fighting spirit’ within one’s self and seeking support can be considered positive means of coping involving long-term psychological adjustment. Denial, lack of self-control, escapism, helplessness, fatalism, and anxious preoccupation are considered negative coping strategies that are mostly associated with poor mental health. Drawing on Lazarus and Folkman’s works on stress and problem-focused and emotion-focused coping, the select six breast cancer memoirs are analysed to discover the coping strategies employed by the narrators to engage in self-reconstruction. Building on Lazarus and Folkman's theoretical model on stress and coping, chapter four attempts to introduce a crucial framework for autobiographical reconstruction. This coping mechanism can help us understand the significance of various major and minor coping strategies used by memoirists to overcome the adverse effects of biographical disruption.

1.8.4 Analytical Framework

The thesis uses narrative analysis as an analytical tool to examine personal accounts of a few individuals who have experienced breast cancer and to focus on understanding how these people construct their experiences, the themes they emphasise, and the meanings they derive from their journey with the disease. A narrative analysis is the process of "taking as its object of investigation the story itself " (Riessman, 1993, p. 1). Illness stories are narrated by the patients "to make sense of their world because humans understand their lives as lived stories" (Bury 2001, Kenny et al. 2017). Bury (2001) explains that narrating illness can repair the 'disruption in a patient's life', cope with the psychosocial problems and challenges, and result in self-discovery. A narrative analysis will look for how the story is told: Is there a plot, and what kind of plot? Describe the characters: Who is the antagonist, or protagonist? What is the setting (space, time)? What language is used: What symbols, metaphors, and word meanings appear in the transcript? How does the story reflect the subject's society, culture, politics, and history? What is the purpose of the story? (Klugman, 2019, p. 261). According to Bury, the study of chronic illness narratives can reveal various important issues like identity, experience and 'late modern' cultures (2001, p. 264).

An analytical framework has been developed by Bury to explore three levels of narrative formation in the face of illness: 'contingent narratives' explain the proximate causes of illness and the practical, disabling effects of its symptoms, 'moral narratives' focus on the changing relationship between the person, the illness and social identity, and 'core narratives' reveal the connections between the layperson's experience and the deeper cultural meaning of illness and suffering. The six memoirs chosen for the current study include the meaning-making process through the levels of contingent narratives, moral narratives, and core narratives. Each of these memoirists initially focuses on bodily symptoms of illness as causes of disrupting situations in terms of both body and mind. Thereafter, they think about the illness and how it has changed their social identity. Next, they attempt to find out the deeper cultural meanings of illness overcoming mere bodily suffering and psychological distress. The current study will involve all three levels of narrative formation as they are interrelated with each other.

The narrative analysis as a tool has two levels of significance: firstly, it helps in studying the process of dealing with the experience of falling ill; and secondly, understanding the personal and shared meanings that illness experience provides us with (Leimumaki, 2012, p. 257). To any researcher, the lived life of an individual is not identical to her narrated experiences. In between these two, the conceptualisation and verbal transition take place. The whole process of narrativisation is based on the intention of expressing something personal which can be understood by others. Narrative analysis is one such method that helps us to understand different aspects of narrativisation (pp. 261-2). Narratives are always constructed at a particular moment or in a specific context. A narrative can be analysed as a continuous process including not only the events but also their causes and consequences (p. 263). For both the listeners and researchers of narratives, this analytic tool provides “a possibility of studying meaning-making from the specific viewpoint of the speaker” (p. 264).

The second chapter of the thesis will mainly focus on exploring different dimensions of fear as a major disrupting emotion among patients. Using the technique of narrative analysis, the attempt will be made to point out the changing nature of fear expressions as expressed through language. In what context, the narrators have experienced fear, how long it persisted, or even what have become the consequences of fear? It might include bodily expressions like shivering, stammering, crying, and others. The language of patients can also include different images, symbols, hyperbolic expressions, and metaphors to express their moments of fear and death anxiety. The language they have used to narrate the fear expressions has thus become a medium to understand the biographical disruption and its major effects in the form of fear.

The third chapter of the thesis is based on the common theme of shame. Using narrative analysis techniques, this chapter will explore deep and subtle moments of shame in the daily lives of breast cancer patients. Their disability, physical weakness, bodily actions, medical gaze, and the question of social acceptance cause tremendous amounts of shame which are followed through their narration of those events of their life that lead to shame. Similar to the second chapter, the third chapter also points out the metaphors of shame along with bodily expressions like blushing, hiding face, or hesitation in sharing with others. The language used by the narrators along with the metaphors of shame help to express their inner torment otherwise silenced in our society.

In both the second and third chapters of the thesis, the selected three Indian narratives are analysed first to find out the expressions of both fear and shame, the reasons behind those expressions, and their effect on patients' minds. Next, the American memoirs are similarly analysed to find out both the similar and different expressions of fear and shame along with the cultural differences. Therefore, two different emotions are predominantly found in both Indian and American contexts despite the difference in their respective culture and healthcare scenario. Using comparative methods, similarities and dissimilarities are pointed out and discussed in the final discussion section of chapter five.

In the fourth chapter of the thesis, the narrative analysis technique is used to find out and locate the coping strategies used by both Indian and American memoirists which help them in overcoming the biographical disruption and its manifestation in the form of fear and shame. There are around fourteen predominantly found strategies in common in all the six memoirs along with another around twelve occasionally found in a few of these memoirs. All these major and minor strategies together create a possibility of redefining the self, recreating the identity as it was disrupted by breast cancer as a sudden occurrence. The memoirists have not only used their understanding of illness as a meaning-making process but also adopted certain behavioural coping strategies for problem-solving, stress management, and overcoming the troubling effects of emotions. The three Indian memoirs and the three American memoirs that have been chosen for the analysis can only provide a brief overview of the two selected cultures and healthcare scenarios. However, looking at the universality of emotions, the coping strategies used by these memoirists can also be used in other similar situations of biographical disruption where a person's whole life is altered.