Chapter 5

Conclusion

5.1 Introduction

This thesis explores six Indian and American women’s breast cancer memoirs written from the vantage point of two different cultures to gain new insights into the psychosocial burden of breast cancer and to discover the presence of an evolving coping mechanism against the various challenges posed by the disease. Through a comparative study of both Indian and American contexts, this thesis attempts to establish similarities and differences in the way the memoirists negotiate their psychosocial experiences of fear and shame, identified as two important manifestations of biographical disruption caused by breast cancer. This concluding chapter summarises the purpose of this study, discusses the key findings, interprets the results, and presents the limitations and implications of the study. Finally, the current study is situated inside the field of Medical Humanities as the conclusions drawn from the research highlight the silence around breast cancer, the importance of patients’ subjective emotions, and individual coping strategies to overcome the emotional burden. The potential contributions to the field of medical humanities will be presented along with recommendations for future scope of research that might offer further insights into our understanding of women’s experience of breast cancer.

5.2 Purpose of the Study Revisited

The purpose of this study was to explore how the concept of biographical disruption also extends to breast cancer as a sudden and significant event that cardinally changes one’s course of life and how women with breast cancer undergo several psychosocial burdens caused by the disruption and cope with them to accept the new normal. The purpose was to approach this exploration from the standpoint of the discipline of Medical Humanities, hoping to maintain justice against the silencing of patients both inside and outside healthcare, striving to enhance the coping mechanism of breast cancer patients struggling with the consequences of the illness.

The study investigated how breast cancer also causes biographical disruption in the lives of those diagnosed with the disease by severely altering and threatening one’s self-identity and how it disrupts one's social and cultural experience by evoking challenging emotions like fear and shame. Originally, the concept of biographical disruption was developed by Michael Bury (1982) in the context of Rheumatoid Arthritis. and since then, there has been very scant research recognising breast cancer as a source of biographical disruption (Liumputtong & Suwankhong, 2015). This study, through the analysis of the select breast cancer memoirs, reveals how such illnesses challenge the normal structures of everyday life, forcing individuals to reassess their self-concepts, roles, and plans. In doing so, the study extends the scope of biographical disruption to include breast cancer as a potential trigger of such a disruption as the disease is not only a significant medical condition but also a profound personal and social experience that can drastically alter an individual's life trajectory. The study also reveals that the diagnosis and subsequent treatment processes involving breast cancer also present the characteristics of what Bury considers as "biographical disruption," suggesting how a person's expected life course is interrupted by chronic illness. Using Lazarus & Folkman's coping framework, the analysis identified twenty-seven important major and minor coping strategies used by the six breast cancer memoirists selected for this study. Thereafter, the thesis also goes beyond the coping framework propounded by Lazarus & Folkman to explore the presence of a distinct coping mechanism, an Autobiographical reconstruction Mechanism (ARM) with five important components used by the women narrators to reconstruct their otherwise disrupted identities in an autobiographical manner.

5.3 Research Methodology Revisited

The decision to adopt narrative analysis as a methodology for examining the six breast cancer memoirs was based on the aim of the study which was to explore the expressions of fear and shame along with the coping mechanism from breast cancer patients' memoirs of both India and America. The rationale behind the selection of the six memoirs for this study and a narrative approach to the analysis of those memoirs allowed me to critically understand the emotional burden of breast cancer by interpreting the patients' subjectivity towards the problem as well as the probable solution to bring back the agency over the self-in-crisis. Central to this methodological approach was the belief that to grasp the meanings women make from their lived experiences we must listen to the patients' voices for a better understanding of their emotional burden and coping with it. Hence the selection of texts was justified. As three memoirs belong to the Indian genre and three others to the American genre, they provide a comparative approach to evaluate the nuances of the same problem.

5.4 Summary of Key Findings

Analysis of the six select breast cancer memoirs revealed a certain amount of diversity in experiences. Most of the women narrators under consideration are married, and one of them (Tig) is unmarried and lesbian. Two of them are childless (Minakshi and Shormistha), and others have kids except Tig who aspires to have one. Their economic dependency and socio-cultural background are not similar which provides the present study with a challenge to understand a varied source of lived experiences in breast cancer. Even though the purpose of this study is not to summarise and generalise, some significant points of this research contribute a valuable addition to the existing literature.

In the second chapter *Beyond the Lump: Grappling with Fear and Anxiety*, all the six memoirists chosen for this study expressed their fear in varied dimensions. Among the Indian memoirists, Minakshi Chaudhry's fear of breast cancer was expressed even much before her encounter with the illness. Her previous perception of breast cancer as a cause of death in her close group of acquaintances made her fearful on the first occasion. While undergoing the painful treatment of breast cancer, she was so scared that she even developed suicidal tendencies. On the other hand, Neelam Kumar focused more on coping against the dominating emotion of fear and Shormistha Mukherjee challenged cancer vis-à-vis death. Among the American memoirists, Tig Notaro's fear of breast cancer was related to her fear of loneliness, as she was desperately looking for love, support, and empathy in her difficult times. Her initial shock at the bad news was gradually transformed into her desperate wish to risk her life to give birth to her biological child. Similarly, Nina Riggs felt an extreme level of fear of leaving her children alone in the world after her death. At the same time, Anne Boyer generalised her fear by combining it with the general pain and suffering of human beings.

Other than these individual perspectives towards fear, they all expressed a few common fears universally present amongst them, like fear of chemotherapy, waiting time for doctors' appointments or reports, fear of difficult medical jargon, and fear of silence surrounding the disease 'cancer'. These fears were so strong that they were even haunted in their dreams or imaginations. Both the Indian and the American memoirists experience the fear of cancer mostly because of the communication gap between doctors and patients, excessive use of medical jargon unknown to them, short span of examination, long waiting time, and fragmented healthcare systems promoting treatment under many specialists. Even in the twenty-first century's digital era of awareness, most of them recorded the apathy of nurses or healthcare professionals, and the hesitance to pronounce the word 'cancer' as it intensified fear in them. Thus, voicing their fear helped them restore empathy for themselves and other cancer patients, and it also developed an open-minded approach to the disease. However, there are a few cultural differences found during the analysis of fear between the Indian and the American patients. First, cancer mostly confronts Indian patients with questions like "Why me?", arose out of fear, private anguish, and open protest. Although Indian understanding of suffering, disease, and death is deeply rooted in the sociocultural belief of punishment due to some sins, the Indian memoirists expressed their strong willpower and confidence through their narratives as for them there is no unsurmountable fear. Similarly, both Indian and American women overcome the fear of surgery-related disfigurement, fear of dependency, physical disabilities during chemotherapy sessions, and associated identity crises gradually through sharing their stories of breast cancer.

Significantly, some unique differences were noted in the fear metaphors used by both the Indian and American breast cancer memoirists. The metaphors like two ferocious tigers (for two tumours), a suspicious country (for death), bones turning into jelly, throats getting dried, and the comparison of fear with a shaking leaf, darkness, roller coaster, dangling in purgatory (in between life and death), and no-turning-back zone are quite commonly found in both Indian and American patients. The Indian patients uniquely used some metaphors like lifeless bodies, ice-cold water, and the transformation of bone into jelly to showcase the intensity of their fear. As everyone's fear is different, their understanding of the same emotion can also differ. As most of the patients are married, they mostly showcased their fear of their overdependency on their spouse, losing their partner, or being disqualified from the responsibilities of motherhood. Such fear is identified as most common fear in recent research on breast cancer too (Panitz & Bobos, 2023, p. 244). However, it was noticed that fear is associated with many other life situations and that the expressions of fear are also different for every individual.

In the third chapter, *It Plays on the Body and Mind: Encountering Shame and Crisis of Self*, all the memoirists display shame related to their breast cancer experiences and the self-crisis caused by the embarrassment in both private and public. There were many common signs of shame-induced actions narrated by the memoirists—stammering, not making eye contact, avoiding public appearance, and wearing wigs to cover chemo-baldness. This chapter foregrounded both the physical and the mental struggles; therefore, their reactions to shame created a play between the body and mind. Breast cancer and the post-mastectomy scarred body are extremely tormenting for women belonging to any culture, even after the massive availability of biomedical facilities in healthcare services. In this chapter, a few expressions of shame were noted, which were exclusively present in breast cancer patients, and a few expressions of shame were common to every sick individual suffering from any such chronic illness. There were some stark differences in the cultural understanding of shame and breast cancer in both the Indian and American contexts. Indian patients still undergo a profound struggle to discuss their breast cancer-related issues with their family members or discuss the symptoms with male doctors because of the de-normalisation of breast talk in India. American memoirists never displayed such embarrassment in their narratives, although they felt ashamed to express their shame as Western culture forcefully maintained silence about experiences of shame as it is considered to be against empowerment.

The experiences of physical changes were mandatorily present in every individual undergoing the process of biographical disruption. However, Western breast cancer culture's celebration of survivorship and the cosmetic industry's upper hand have a huge potential to silence the possibility of change or transformation. All three American memoirists highlighted that the use of prosthetic breasts, wigs, or even getting tattoos over the scars was so normalised that they felt hardship in expressing the shame associated with their baldness, bodily abject, excretions, unevenness, or post-surgery scars. On the other hand, Indian memoirists mainly expressed their struggle with accepting themselves against feminine beauty standards. Most of them accepted wigs, prosthetic breasts, padded bras, or reconstruction surgery to empower themselves to beautify their bodies or bring back the agency of their previous selves. Only Shormistha Mukherjee attempted to oppose the desire to look feminine and attractive. Nina Riggs and Tig Notaro also showed this ambiguity, as they sometimes felt ashamed of their bodies and sometimes revolted against the already existing beauty standards. In the Indian context, patients felt more uneasy because of the whispering about breast cancer and nurses' or doctors' apathy towards patients. Indian memoirists particularly marked such cases where the patients often switch from one doctor to another, a more empathic one. Even patients like Tig Notaro and Nina Riggs felt confident about their imperfections or scarred bodies only after their partners or spouses admired them.

The journey from shame to acceptance was difficult for each patient chosen for the study. Many instances in the memoirs were found where people around patients whisper about the disease, do not know how to react in the situation or end up showing extreme levels of sympathy that make the patients uncomfortable. The biomedical process of care ignores the subjectivities of patients as their sick bodies invariably bring them the 'sick role' assigned to them. Due to an excessive amount of dependence on biomedical apparatuses and tertiary sources of diagnosis, an extra amount of consciousness is caused by the measurement of health by mammography plates, digital monitors, MRI scan machines, blood test apparatuses, injection devices, and diagnosis reports. People's averting gaze, using the "c-word" instead of cancer, whispering, and awkward reactions also create difficulties in accepting themselves. Indian memoirists visualised their problems related to shame with many unique expressions, like comparing mammograms and MRI scans with a boob grinder machine and a supersonic toaster, and thereafter, the portrayal of blushing male gynaecologists while having breast talk with patients. The memoirists also commonly felt ashamed of their look with no hair, no eyelashes, dark circles, and post-mastectomy scars on the body. Therefore, whether she is an Indian or an American, physical changes always bring a crisis to one's understanding of the self. However, all the memoirists found unique ways to overcome trauma related to shame.

In the fourth chapter, *Towards Autobiographical Reconstruction: Coping with Breast Cancer Challenges*, based on the analysis I identified twenty-seven coping strategies used by Indian and American memoirists. This thesis not only explores the differences in cultural expressions of breast cancer in Indian and American scenarios but also identifies the major and minor coping strategies used in both cultures. Using metaphoric visualisation, humour, introspection, and other important coping strategies helped all six breast cancer memoirists under discussion to reintegrate body and self. Tig Notaro used fulfilling the wishlist and Anne Boyer used to think about the afterlife as a unique individual coping strategy to cope with breast cancer. Similarly, Minakshi Chaudhry used self-criticism and Neelam Kumar used spirituality as their coping strategies, which supported their individuality in overcoming the burden of breast cancer. A few common coping strategies were almost found in every individual patient: denial of the negative, acceptance of fate, restoring hope, gathering courage, and bringing positivity to life. However, normalising breast talk is a peculiar Indian phenomenon found in all three Indian breast cancer memoirs. Therefore, coping with life-writing became an important part of reflecting on the self. Nina Riggs and Anne Boyer represented themselves differently in their language and expression of autobiographical writing as they were already established writers by profession. However, Tig Notaro and other Indian memoirists except Minakshi Chaudhry tried their hands for the first time while writing their memoirs. Through writing their books, these memoirists completed the journey both as breast cancer patients coping with physical and psychosocial challenges and also as writers reconstructing their disrupted selves in an autobiographical manner.

By identifying the coping strategies, this research mapped five major components in the identity reconstruction process employed by the memoirists. The five components – recollection, reflection, integration, emotional processing, and meaning-making – were then organised in a manner to propose the Autobiographical Reconstruction Mechanism (ARM) which the thesis claims to be an original contribution towards our understanding of the unique coping mechanisms developed by breast cancer patients when they are faced with an existential crisis. Despite the differences in cultures, beliefs, and healthcare systems, these memoirists created a community for themselves by sharing their insights and coping mechanisms to fight against breast cancer. The Autobiographical Reconstruction Mechanism (ARM) including the five important components, is one such significant coping mechanism that is not only applicable to breast cancer patients for winning over challenging emotions; rather, it has broad implications as the same coping strategies can be used by others who face similar challenges due to biographical disruption caused by any life-changing incident, including breast cancer. Through recollecting life events, reflecting on them, integrating them, processing emotions, and meaning-making, the select women narrators reclaim their self and agency and create a new normal for themselves. Self-writing is considered a major medium of introspection, which plays a major role in caring for the self (Batters, 2011, p. 6). All five components of the Autobiographical Reconstruction Mechanisms (ARM) are directly or indirectly related to self-care and identity formation.

Recollection is the first among the five components of the ARM, as the patient's memory is involved in the process of recalling all events that are directly related to a person’s episodic autobiographical memory, which not only helps in re-experiencing those but also helps in understanding their specific details (i.e., in Spatio-temporal context, factual and emotional traumatic events) (Piolino et al., 2009; Tulving, 2002). It is generally difficult to recall traumatic events from the past, as patients often risk reliving the moments while recalling them. There are various negative emotions involved in the process, for instance, shame, anxiety, fear, and guilt, among others. However, the conscious act of recollecting the physical pain, emotional trauma, and daily life's alteration creates the first step to getting back to the normalised self.

The second important component of ARM is reflection. In the first step, recollection, patient narrators explore various factors that have influenced their lives, such as family and relationships. In the second step, reflection, the narrators recognise the external forces that have shaped their identities while enabling a conscious effort to redefine or reaffirm the possibility of renewal. Reflection provides them with the opportunity to rethink their recollected life experiences and constructed self/identity. It also helps introspect and enhance a developed self-awareness crucial for reconstructing the self. A patient's initial understanding of the self is modified to a well-developed and better understanding of the self in this step of ARM.

Integration is the next step and the third major component of ARM. After recollecting both the positive and negative life experiences, it becomes important to organise them coherently. Many studies reveal that patients during or after the stressful chemo treatments lose their cognitive abilities, which are referred to as chemobrains (Morel et al., 2015; Wefel & Schagen, 2012). However, storytelling provides them with a scope to envision the illness as a battle, a journey, or a story of fortunate survival. The ill body or the ailing self is, therefore, plotted inside the story where the distinct events create a coherent whole. As there is always a difference between the lived experiences and the narrated experiences, the sequence of narrated events inside a memoir needs to be different from the sequence of actual life events. Overcoming the effects of chemobrain, the patient-narrators in the chosen memoirs restore their cognitive abilities by integrating a range of diverse experiences into a coherent narrative. Besides embracing the entirety of their journey, the narrators build a more integrated and resilient identity for themselves.

The fourth step in ARM is emotional processing which helps to express the natural reaction or outcome of expressions in a certain context. Emotional processing refers to the way individuals understand, manage, and work through their emotions. It involves recognising and making sense of emotions, and the emotions need to come out either in their real or in their modified form. Emotional processing helps the narrators channel their emotions to acknowledge feelings of anger, sadness, fear, anxiety, and shame. The present study establishes there are many occasions when patients express anger while being scared, or they use forceful laughter to hide their sadness. Emotional processing enables the narrators to understand, express, regulate, integrate, and work through their difficult emotions and find a sense of acceptance.

The fifth step in ARM is the meaning-making process, which consists of moments of growth, learning, and achievement. It allows the narrators to not only just record their experiences but also acknowledge both their strengths and weaknesses. Through this process, they also identify the patterns of their reactions in the face of struggles, and thus they set new goals for self-management and personal development. This meaning-making occurs in continuity as the meaning derived at an earlier point might change at a later point. Therefore, this last component of ARM creates a dynamic and evolving sense of self/identity for patient-narrators.

Despite being different in nature of disease, stage of diagnosis, treatment procedure adopted, health beliefs, and understanding of disease, all the coping strategies identified under the Autobiographical Reconstruction Mechanism (ARM) are effective for every individual in such life-altering situations. For instance, self-reflection strategies like introspection, understanding the value of life, and metaphoric visualisation help patients improve their quality of life even after knowing about suffering, pain, and death. Similarly, meaning-making strategies like growing self-love, understanding different dimensions of illness and practising gratitude help bring individual growth.

5.5 Significance of the Study

The six narratives selected for the study offer a profound insight into the lived experiences of those battling breast cancer, with the potential to drive improvements in healthcare delivery, patient support, and medical research.

5.5.1 Humanising Patient Experience

The biomedical approaches, predominantly followed in healthcare institutions, mostly focus on the biological aspects instead of "existential aspects of illness" and the "subjective experiences of being ill" (Kidd & Carel, 2017, p. 176). Breast cancer memoirs bring a deeply personal dimension to the clinical data, offering a human face to the statistics. By sharing their journeys, the six breast cancer patients provide a nuanced understanding of the emotional and psychological impacts of the disease beyond the clinical symptoms and treatment protocols. Therefore, more such studies can facilitate the humanisation of patients' experiences and can also help healthcare professionals develop greater empathy and compassionate care.

5.5.2 Identifying Gaps in Care

Memoirs often reveal gaps in the healthcare system that might not be apparent through conventional feedback channels. All six memoirists included both positive and negative feedback about the treatment process and the care they received from doctors or other healthcare professionals. The thesis also reveals how patients might describe experiences of inadequate information, poor communication from healthcare providers, or difficulties navigating the medical system. All six memoirists note how they journey through disturbing experiences of fear and shame often caused by these previously stated reasons. Therefore, these insights can highlight areas in healthcare services that need to improve, such as better patient education, clear communication, or more streamlined processes.

5.5.3 Shaping Patient-Centered Care

The stories shared in these six memoirs emphasise the importance of patient-centred care – an approach that prioritises the patient's preferences, needs, and values. By understanding what matters most to patients, healthcare providers can tailor their approaches to treatment and support, making care more individualised and effective. For example, patients like Nina Riggs and Tig Notaro describe how personalised support groups or flexible treatment options have made a significant difference in their journeys. Anne Boyer criticised the objective and empathy-less approach of treatment like other Indian patients. Thus, all the Indian patients had to find solace in the support received from their close friends and family members.

5.5.4 Driving Research and Innovation

Breast cancer memoirs can also inspire new avenues for research. Personal accounts might shed light on aspects of the disease or its treatment that have not been thoroughly explored. For instance, a memoir might reveal the psychological challenges of dealing with long-term side effects of treatment, prompting researchers to investigate ways to mitigate these issues or develop new therapeutic strategies. As the facilities are also not the same for Indian and American scenarios as discussed by these memoirists, the approach for treating patients needs to be different. Therefore, improvements can be made in developing countries like India by incorporating awareness about self-examination and promoting breast talk both inside and outside the hospital care system.

5.5.5 Supporting Emotional and Psychological Well-being

The therapeutic value of writing and reading memoirs cannot be understated (Chandler, 1990). Memoirs provide a space for deep self-reflection, and using this medium, the six narrators bring validation to their personal experiences of biographical disruption. For many patients like these six memoirists, writing their memoirs provides a means of processing their experiences and finding a sense of closure. For others, reading these accounts offers solace and validation and reduces feelings of isolation.

5.5.6 Enhancing Patient-Provider Communication

All six memoirs selected for this study underline the importance of clear, empathetic communication in healthcare settings. By sharing their experiences, the patients also highlight the impact of communication styles and strategies on their treatment journey. Healthcare providers can use these insights to refine their communication skills, ensuring that patients feel heard, understood, and supported throughout their care. Therefore, these memoirs become influential tools to overcome epistemic injustice that often occurs unknowingly or unintentionally inside healthcare (Boesky, 2015; Carel & Kidd, 2014).

Medical practitioners can understand the emotional vulnerabilities in terms of fear, anxiety, shame, and other difficulties in patients. They can be more sensitive and empathic in their perception of physical and emotional damage to patients. More studies like the present one will encourage family members to break their silence on the disease and openly talk about it. Thus, breast talk in the context of breast cancer can be normalised in countries like India just like in Western countries. Treating cancer patients as sinners, hiding information from them, and unwillingness to pronounce the word ‘cancer’ also can be changed in the Indian context.

These memoirs not only record the important coping mechanisms but also build a community with others who face similar challenges. Such mechanisms with their significant components effectively help in improving self-management skills after a major strike of biographical disruption. This study has conceptualised breast cancer as a major reason for biographical disruption which will broaden the understanding of the challenges of breast cancer for future research. Lazarus and Folkman’s coping framework is also extended in the current study to construct a well-developed Autobiographical Reconstruction Mechanism (ARM) which helps in understanding the strategies employed by patient narrators in identity formation.

5.6 Future Directions

During the analysis of the memoirs, it was observed that the women narrators used several metaphors to express difficult emotions and ambiguous feelings, which are otherwise difficult to express in logical and empirical language. As the present study is limited to finding the differences in emotional burden as well as coping strategies employed by both the Indian and American breast cancer patients, it could not have explored the therapeutic use of metaphorical expressions. A further study is possible in this area, as all the memoirists used unique metaphors with the strong power of visual imagination. There were very less similarities in metaphorical expressions as the memoirists were very much individualistic in their approach. Due to the limited availability of Indian breast cancer narratives, the current study provides us with a limited point of view. The same situation of breast cancer might be more challenging for unmarried women from Indian rural areas. Similarly, a lesbian woman or a non-survivor tale from the Indian genre might provide more insightful input in the understanding of challenges in coping. The narratives produced by women from financially unstable backgrounds and rural areas, who have less access to expensive treatment in cancer, can be studied to include the neglected sides of a similar problem. When a person's understanding of oneself (biographical identity) is disrupted through any form of biographical disruption, the reconstruction of self becomes necessary to take care of self. Many such studies are required to understand similar problems in a varied context because all patient's narratives are important as they are significantly different from each other.