

**SELFHOOD AND NARRATIVE AGENCY: A STUDY OF INDIAN LIFE-  
WRITING AND FICTION ON PHYSICAL DISABILITY AND MENTAL  
ILLNESS**

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**Doctor of Philosophy**



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### **Declaration**

I do hereby declare that the dissertation titled “**Selfhood and Narrative Agency: A study of Indian life-writing and fiction on physical disability and mental illness**” is a research work carried out by me in the Department of Humanities and Social Sciences, Indian Institute of Technology Guwahati, under the supervision of Dr. Kiran Keshavamurthy, for the award of the degree of Doctor of Philosophy. No part of this thesis has been submitted to any University or Research Institute for the award of any degree of diploma.

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**November 2023**



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**Certificate**

This is to certify that Shibashish Purkayastha has prepared the dissertation titled “**Selfhood and Narrative Agency: A study of Indian life-writing and fiction on physical disability and mental illness,**” for the degree of Doctor of Philosophy at the Indian Institute of Technology, Guwahati. The work was carried out under my supervision and in strict conformity with the rules laid down for the purpose. The thesis is the result of his investigations and has not been submitted either in whole or in part to any other university/institution for a research degree.

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## Table of Contents

Declaration  
Certificate  
Acknowledgements  
Table of Contents

### ABSTRACT

1-2

### INTRODUCTION

3-68

### CHAPTER ONE

69-122

**Therapeutic counter-narratives: Reading Gayathri Prabhu's *If I Had to Tell It Again*, Swadesh Deepak's *I Have Not Seen Mandu* and Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia*.**

### CHAPTER TWO

123-162

**Caregiving and narrative agency in Pankaj Varma's *Silver Haze*, Himanjali Sankar's *Mrs. C Remembers*, Shama Husain's *Psychlinis* and Tito Mukhopadhyay's *Beyond the Silence: My Life, the world and Autism*.**

### CHAPTER THREE

163-206

**Embodiment, subjectivity and self-identity in Shabri Prasad Singh's *Borderline*, Joginder Paul's *Blind*, Anirban Mukherjee's *In a Train to Trivandrum*, Amandeep Sandhu's *Sepia Leaves* and Jerry Pinto's *Em and the Big Hoom***

### CHAPTER FOUR

207-270

**The self-reliant human subject: Narrativizing human-rights in Reshma Valliappan's *fallen standing: My Life as a Schizophrenist*, Preeti Monga's *The Other Senses*, Shivani Gupta's *No Looking Back* and Sarmistha Pritam's *Sun on My Face***

### CONCLUSION

271- 280

### BIBLIOGRAPHY

281-325

**Selfhood and Narrative Agency: A study of Indian life-writing and fiction on physical disability and mental illness.**

**Abstract**

This dissertation argues that Indian life-writing and fiction on physical disability and mental illness in the early twenty-first century have portrayed individuals as exercising selfhood and agency by not merely charting a transformation from dependency towards independence but by also narrativizing and thereby, embracing the inconsistencies, ambiguities, fragmentariness and polyvocality inherent in their identities. This unique portrayal of disability and mental illness, I submit, will contribute to a more diverse and inclusive literary landscape. Although the narrators in the selected texts grapple with substantial challenges stemming from their physical disability and mental illness, which deeply impact their self-image and interactions with others and the world, they are dedicated to examining unconventional approaches to life and coexistence. Their exploration goes beyond simply trying to alleviate the trauma and suffering caused by their medical conditions. These narratives underscore the significance of sharing one's distressing life experiences through life-writing and fiction as a vital aspect of living with disabling conditions. This act plays a crucial role in reclaiming one's agency and sense of self. Firstly, the novels and life-writing serve as therapeutic counter-narratives by positing an alternative worldview which does not merely focus on the curative effects of medicine, counselling and therapy but also on the individuals' autonomy and choices regarding their own healthcare and support systems, as well as to promote a holistic understanding that considers both medical and social factors in addressing these issues. Secondly, the life-writing and fiction, in some cases, engage in a collaborative narration between the disabled and mentally ill protagonist or the narrator and their caregiver, which in some cases may promise

empathy. Thirdly, the lived body acts as the locus of experience through the ideas of embodied narration and [bodily] memory, and fourthly, some of the life-writing and fiction question the idea of human-rights by sharing their personal experiences of discrimination, stigmatization, and marginalization, which serves to shed light on the systemic barriers that hinder their access to education, employment, healthcare, and social inclusion. The study unfolds through a comprehensive review of relevant literature, spanning fields such as literary disability studies, mental illness and literary studies, life-writing, fiction, narrative theory, selfhood and narrative agency, and health humanities to provide a firm theoretical foundation. It explores how the select literary narratives can function as tools for self-expression and self-discovery. In this dissertation, I also aim to demonstrate that works of fiction and life-writing addressing physical disabilities and mental illnesses in the Indian context are inherently intertwined with issues related to family dynamics, gender roles, ethnicity, caste, and social class. In my analysis of these narratives, I place particular emphasis on whether these autobiographical accounts challenge the conventional limits of life-writing and fiction. By doing so, I intend to highlight the corporeal nature and malleability of the structure of these life-writing and fiction. In conclusion, this dissertation shows the interdependence of selfhood and narrative agency in the selected literary texts on physical disabilities and mental illness. It highlights the transformative power of storytelling in shaping not only individual self-conceptions but also collective understandings of identity and authorship. The research attempts to contribute to the ongoing dialogues in the fields of literary disability and mental health studies, health humanities, and narrative theory, shedding new light on the dynamic relationship between the act of storytelling and the construction of selfhood and agency in an ever-evolving literary landscape.

**Keywords:** selfhood, agency, life-writing, fiction, disability, mental illness

## Introduction

My cocoon becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court. But the body doesn't easily leave behind its old habits. Once you have been immobilized for two months, every remaining movement is rife with an almost sexual tension. With a half-turn of my ankle, I return under the covers, my legs extended. I reach out, feel for a pencil, and push it back and forth. The gesture is slow, even laborious, but not awkward. It's like a dance, a sort of grace. I am on my feet again. I am everywhere. I see the French ambassador, the mother of my children. I observe my companions, my wife, my countrymen. I think of the places I have been, the men and women I have known.

--Jean-Dominique Bauby (Jean-Do) in *The Diving Bell and the Butterfly*

In the lines quoted above, Jean-Dominique Bauby, the protagonist of the movie *The Diving Bell and the Butterfly* (2007) compares his physical condition to a cocoon where he is essentially imprisoned within his own body due to locked-in syndrome.<sup>1</sup> The cocoon is a symbol of confinement and immobility that describes his feelings of entrapment. Despite his physical immobility, Bauby believes that his mind can soar. Bauby describes his inner world and his creative imagination that remains free. His consciousness is compared to a butterfly, which is a symbol of the boundless potential of the human mind. The lines convey a sense of optimism and possibility. Bauby acknowledges that, even in his profoundly disabled state, there are countless opportunities for his mind to wander and explore. He suggests that the human spirit can negotiate with its physical limitations through the power of the imagination. The references to specific places and times symbolize the boundless potential of the human spirit which can thrive even when the body is severely restricted. Tierra del Fuego represents a

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<sup>1</sup> "Locked-in syndrome is a neurological condition in which a person is conscious and aware but unable to move or speak due to complete paralysis of nearly all voluntary muscles in the body, except for possible vertical eye movement and blinking. This condition is typically the result of severe brainstem damage or injury, often caused by conditions like brainstem strokes, traumatic brain injuries, or other neurological disorders." ("Muse Headband: Potential Communication Tool for Locked-in People" Kaihao Tian)



remote and exotic location, while King Midas's court alludes to a mythical and opulent realm. Bauby is highlighting his ability to mentally travel to any time or place. In these lines, Jean-Dominique Bauby expresses the film's central theme of resilience, the power of the human imagination, and the capacity to find beauty and meaning in the face of adversity. In the primary texts under study, the central character articulates a sense of self that is produced by the constraints of their body and mind. Despite the strong mental desire for movement, Bauby acknowledges the physical limitations that remain after a prolonged period of immobilization. The reference to "immobilized for two months" and the description of every movement carrying "almost sexual tension" highlight the struggle and effort required to regain physical mobility. Bauby describes the act of reaching for a pencil and pushing it back and forth as a slow and laborious, yet graceful, dance. This suggests that even simple movements take on profound significance and beauty for someone living with a disability.

In the exploration of Indian life-writing and fiction concerning disability and mental illness, this dissertation delves into the intertwined realms of selfhood and narrative agency. The current study aligns with the evolving landscape of literary disability and mental illness studies, narrative and cognitive approaches to literary studies that scrutinize concepts such as self, identity, and agency, amongst others. The terms "self," "identity," "selfhood," and "agency" are taken from various academic domains, particularly within the fields of psychology, philosophy, and narrative theory. In psychology, the concept of self pertains to an individual's understanding of themselves, including their thoughts, feelings, and experiences. Identity, on the other hand, refers to the characteristics, beliefs, and values that distinguish one individual from another. Philosophically, thinkers like John Locke and David Hume have contributed to the understanding of the self and identity, exploring questions about personal identity and consciousness. In philosophy, agency refers to the capacity of individuals to act independently and make their own choices. It encompasses the ability to initiate and control

actions, influencing one's own life and the world around them. Agency is often discussed in moral philosophy, psychology, sociology, and literary theory. The exploration of selfhood and agency within the context of narrative is drawn from narrative theory and literary studies. Narrative theory examines the role of storytelling and narrative structures in shaping individual and collective identities. Scholars like Paul Ricoeur, Hayden White, and Mikhail Bakhtin have made significant contributions to narrative theory, discussing how narratives shape our understanding of self and agency. Within the specific context of disability and mental illness studies, these terms are used to analyse how individuals with disabilities or mental illnesses construct their sense of self and navigate agency within societal structures. This interdisciplinary field draws from psychology, sociology, literature, and disability studies to explore the experiences of individuals living with disabilities or mental illnesses. In this dissertation, these terms are used within the framework of literary analysis and disability studies, aiming to understand how narratives of disability and mental illness contribute to the construction of selfhood and agency among Indian authors and characters.

In this context, selfhood or personhood, which I intend to use synonymously in this dissertation, pertains to an individual's journey of evolving self-knowledge from an inability to fully understand themselves to a state of self-awareness. Agency, I maintain, is the ability of an individual to make choices, decisions, and take actions that can profoundly shape the course of their life. The primary attempt of this dissertation is to examine how individuals who are either living with physical disabilities or mental illnesses and serve as narrators in the life-writing and fiction, navigate the intricate terrain of their medical conditions through the lens of their personal experiences. In brief, this dissertation explores how those with disabilities or mental illnesses, grapple with their medical conditions and, in doing so, articulate alternative modes of self-awareness and agency. My avowed aim is to explore how, in the character-driven narratives chosen for analysis, these individuals exercise their autonomy despite the stigma and

vilification around their health conditions. William Fitts distinguishes between two aspects of the self: “the self as an object or structure and the self as a process” (14). In the context of disability and mental illness, the self as an object or structure refers to how individuals are often defined or labelled by their conditions. It can involve how society perceives and categorizes individuals based on their disabilities or mental health diagnoses. This aspect of the self can lead to stigmatization and marginalization. People may be reduced to their conditions, which can limit their opportunities and create a sense of identity crisis. The self as a process, on the other hand, focuses on “the fluid and ever-evolving nature of a person’s identity” (Fitts 14). It recognizes that identity is not fixed but is constantly evolving through one’s experiences, interactions, and personal growth. A person’s perceptions and attitudes depend significantly on her actions, which play a crucial role in acquiring knowledge, solving problems and memory, distinguishing between the inner and outer worlds, and mastering social interactions. Generally, narrative agency refers to an individual’s ability to navigate their immediate narrative environment. It involves the capacity to use, interpret, and reinterpret available narratives, as well as the choices made in narrating one’s life and relationships. According to Hanna Meretoja, the three essential dimensions of narrative agency are “narrative identity, narrative dialogicality, and narrative imagination” (1). As noted by Catriona Mackenzie, narrative agency implies that “being a person involves using narrative capabilities for self-interpretation, leading to the integration of the self over time,” which is dynamic, provisional, and open to change (11-12). According to Meretoja, “narrative agency is not only a process of self-interpretation but also contributes to moral agency as individuals continuously participate in narrative practices that both perpetuate and challenge social structures” (Meretoja 12).

The title of the dissertation is “Selfhood and Narrative Agency: A Study of Indian life-writing and fiction on physical disability and mental illness”. In this dissertation, I argue that

the narrators of the selected narratives on the experiential lived experiences of disability and mental illness develop their own agency and individual identity and thus negotiate their selves within their immediate cultural settings, which is reflective of their lived experiences. Disability and mental illness fiction and life-writing attempt to restore selfhood and agency to persons who are otherwise invisible and unheard. Although the experiences of physical disability and mental illness challenge one's sense of selfhood and narrative agency, I submit, there is a kernel of comprehension of one's self and identity within the personhood of the individual which the narrator's foreground through the various alternative modes of self-expression in their narratives. The act of narrating their experiences enables them to "express themselves and be heard and heeded" as noted by Thomas Smith (9). He observes, "agency... is the ability of individuals to negotiate societal systems to make meanings for themselves that allow them to act, in however circumscribed a manner, in the world" (Smith quoted in Buss 9). Life-writing and fiction according to Smith "effectively reveal agency or the desire for agency because they show how meanings are created for people, how people create meanings for themselves, and how people engage in the world around them" (Smith quoted in Buss 9). I use the term selfhood and personhood interchangeably to refer to the concept of the self, its formation, and its depiction in relation to others is a product of actions and shared communication within a specific cultural context, shaping one's identity.

Over time, the study of selfhood gained prominence, especially as Western individualism became a subject of interest, in contrast to the Eastern focus on collective identity. As Gerhard Reese et.al write-

people view themselves as inherently embedded within a network of interpersonal relationships and assumed social roles. This widespread cultural understanding of selfhood does not rely on some illusive essence to be discovered and expressed. Instead, the self is made unique by its specific constellation of relationships, roles, and social obligations. (Reese 17)

In his essay “Self: History of the Concept”, P. Wagner writes that “the introduction of interaction and intersubjectivity in self-formation has created intermediate theoretical positions, and, possibly more importantly, they have allowed different accentuations of selfhood without making positions mutually incompatible” (Wagner 1). Since the mid-1970s, theoretical and empirical developments in the field of literary studies and the social sciences have foregrounded the notion of the ‘decentering of the subject’ from the standpoint of poststructuralist theory. On the other hand, the term postmodern identity has been coined giving rise to a new form of selfhood. Both the poststructuralist and the postmodern views of selfhood “problematize the conventional understanding of selfhood, namely the existence of the human self as the unit and persistence of the same self over time” (Wagner 12). Stanley Cavell’s “reflections provide an example for a thinking about selfhood that does not presuppose an idea of identity, coherence, or consistency” (Cavell 19). He “cautions against any fixed, metaphysical interpretation of the idea of a self” and against the idea of ‘a noumenal self as one’s “true self” and of this entity as having desires and requiring expression” (Cavell 20). In the essay, “A Corporeal Narratology?” (2003), Daniel Punday observes that

narratives are corporeal not simply because they need to use character bodies as a part of the narrative itself, but also because of the ways in which we think about the narrative structure as reflecting the paradoxes of the body such as its ability to give rise to and resisting a particular pattern (46).

The texts that I propose to study in this dissertation include Gayathri Prabhu *If I Had to Tell It Again* (2017), Shreevatsa Nevatia’s *How to Travel Light: My Memories of Madness and Melancholia* (2017), Swadesh Deepak’s *I Have Not Seen Mandu* (2021), Tito Mukhopadhyay’s *Beyond the Silence: My Life, The World and Autism* (2001), Shama Husain’s *Psychlinis* (2018), Himanjali Sankar’s *Mrs. C Remembers* (2017), Pankaj Varma’s *Silver Haze* (2014), Jerry Pinto’s *Em and the Big Hoom* (2012), Shabri Prasad Singh’s *Borderline* (2017), Amandeep Sandhu’s *Sepia Leaves* (2006), Anirban Mukherjee’s *In a Train to Trivandrum* (2019),

Joginder Paul's *Blind* (2016), Reshma Valliappan's *fallen standing: My Life as a Schizophrenist* (2015), Sarmistha Pritam's *Sun on My Face* (2014) Shivani Gupta's *No Looking Back: A True Story* (2014) and Preeti Monga's *The Other Senses* (2012). In the aforementioned literary texts, individuals living with either physical disabilities or mental illnesses are not merely in pursuit of a potential cure for their conditions. These memoirs, autobiographies, and novels do not just depict a transition from dependence to independence and the process of overcoming trauma and indignation. They also celebrate the individuals' self-reliance and self-independence, even in the face of the challenges posed by their disabilities. These narratives emphasize their own fragmented nature, incompleteness, and internal contradictions, prompting a need to reconsider the traditional narrative structure of such works (Purkayastha 4-5). Through a close-reading of both life-writing and fiction, my aim is to explore how the narrators assert their self-identity and their capacity to shape the narrative. I examine how these forms of writing underscore the social model of disability and mental illness, and advocate for changes in societal attitudes, accessibility, and inclusivity, in addition to medical treatments. These perspectives do not necessarily dismiss medical approaches but stress the necessity of a broader societal and systemic approach to addressing disability and mental illness. Furthermore, I investigate how these writers, by narrating their personal experiences, strive to remove the individualized and pathologized aspects of their stories from the cultural repository of narratives (Purkayastha 22).

In the book *Aesthetic Nervousness: Disability and the Crisis of Representation*, (2007) Ato Quayson provides "an overview of disability representation in literature and the arts, arguing that what produces 'aesthetic nervousness' is the breakdown of a text's dominant representational paradigms upon its encounter with disability" (xviii). Aesthetic nervousness emerges because the writer is confronted with a "subliminal fear of the loss of bodily and mental control" (xviii) while narrating their experiences. These literary portrayals of physical

disabilities and mental illnesses possess a profound and tangible quality that blurs the boundaries between the literary narrative and a distinct ethical dimension. This results in a narrative style that can be described as fragmented or elliptical, as the narrator grapples with this complex interplay. (Purkayastha 8). Thomas Mann's views on narration in *The Magic Mountain* (1924) seems pertinent in describing the corporeality of narration, "Let us not forget the condition of life as of narration: that we can never see the whole picture at once— unless we propose to throw overboard all the God- conditioned forms of human knowledge" (574). As Mann makes it evident, "the difficulty of finding one position from which to describe a set of events is attributable to the fluid nature of the human body itself" (Mann 575). As Daniel Punday observes in *Narrative Bodies: Toward a Corporeal Narratology* (2003), "Narratives and bodies circulate, we can say, and in doing so construct a complex textual hermeneutics that cannot be equated with static symbols" (158). By actively exercising their narrative agency and delving into the realm of self-discovery, these writers aim to alleviate distress, albeit partially. They do not just present their experiences as unique but also seek to challenge the notion that life-writing and fiction, at times, rely on a fixed and stable sense of self to establish credibility. However, the ultimate aim of these narratives is not to assuage distress or trauma but to describe the various alternative modes of self-expression, asserting agency and selfhood while embracing their disabled conditions. These narratives serve to promote the agency and autonomy of individuals with disabilities and mental illness by giving them a voice, challenging stereotypes, advocating for their rights, and fostering a more inclusive and understanding society. Eric L. Santner explores the idea of "narrative fetishism" in his essay "History Beyond the Pleasure Principle: Some Thoughts on the Representation of Trauma" where he defines it as, "the construction and deployment of a narrative consciously or unconsciously designed to expunge the traces of the trauma or loss that called the narrative into being in the first place" (14). So, "narratives when fetishized, can become a way of shutting

our ears to what hurts and scares us the most, a way of not merely bringing to the forefront our experiences, but also ridding oneself of the experiences resulting from the social ostracization and vilification” (Santner 15). The underlying motivation for selecting this title was to explore how these writers, in narrating their experiences or transforming them into a narrative, influence the structure of the narrative itself. This, in turn, calls for a reconsideration of the form of these memoirs, autobiographies, and novels. Ryan Thorneycroft’s well-timed article on “Crip Theory and Mad Studies: Intersections and Points of Departure” (2020) has been influential to my dissertation. In that article, Thorneycroft expresses the view that “the fields of disability and mad studies have not been brought together in a synthesized manner” (14). He explores the similar life experiences of the two disciplines starting from experiences of shame, guilt, essentialism, the power of diagnostic labels, rates of violence, stereotypes, passing and ‘coming out’. He further explores “the theoretical overlaps between the two disciplines including strategic essentialism vs constructionism, opposition to norms, subversion and transgression and the disruption and the problematization of binaries” (Thorneycroft 44). He concludes his article by suggesting possible ways in which the two schools can “forge a collective politics and discusses the possibilities of crippling and maddening dialogues” (Thorneycroft 45). Taking his cue, I examine the therapeutic narrative potentials of literary narratives of disability and mental illness, the relationship between the care-giver and care-receiver and its centrality to exercising narrative agency, the focus on the experiential lived experience as the source of understanding their embodied conditions and the various ways in which the selected narratives posit the idea of the self-reliant human subject against systemic human-right violations. In doing so, I strive to focus on the ambiguity, playfulness and self-referential nature of the select narratives. It is an established fact that people with physical disabilities and mental illnesses experience varying degrees of stigma and social isolation. In the Introduction to his book, *Aesthetic Nervousness: Disability and the Crisis of Representation*



(2007), Ato Quayson defines disability as, “socially regulated parameters that exacerbate the effect of impairment. Impairment, on the other hand, refers to specific physical and cognitive deficiencies that lead to the reduced capacity to fully actualize all aspects of one’s life” (15). Ronald David Laing, a Scottish psychiatrist, is known for his alternative and humanistic approach to understanding mental illness. He challenges traditional psychiatric perspectives and offers a different definition of mental illness. Laing views mental illness as a reaction to a dysfunctional or alienating environment. He believes that individuals diagnosed with mental disorders were often responding to the stresses and conflicts within their families and society. In essence, he opines that mental illness could be understood within the context of the individual’s personal and social circumstances. Laing’s work emphasizes the importance of considering the social and environmental factors contributing to mental distress and argued against overly pathologizing diagnoses. Sigmund Freud, the founder of psychoanalysis, has a different perspective on mental illness. He believes that mental illness is rooted in unconscious conflicts and desires. Freud’s definition of mental illness is based on his psychoanalytic theory, which suggests that repressed thoughts, memories, and unresolved psychological conflicts could lead to various forms of psychopathology. He proposes that mental illnesses are manifestations of these unresolved inner conflicts and traumas, often originating in early childhood experiences. Freud’s approach involves delving into the depths of the unconscious mind through psychoanalysis to uncover and address the sources of mental distress. The well-known French philosopher and social theorist, Michel Foucault made significant contributions to the understanding of mental illness, particularly in the context of society and institutions. His invaluable contributions to the domain of mental illness can be found in several of his books and essays, most notably in *Madness and Civilization: A History of Insanity in the Age of Reason* (1961) and *The Birth of the Clinic: An Archaeology of Medical Perception* (1963). Foucault’s perspective on mental illness is deeply rooted in his broader exploration of power,

knowledge, and social structures. Foucault contends that the rise of modern institutions, such as asylums and mental hospitals, marks a significant change in the management of mental illness. These institutions, in his view, are instruments of social control, where those deemed mentally ill are separated from society, and their behaviour is regulated. Foucault explores how the medical profession becomes increasingly influential in defining and categorizing mental illness. He argues that the “medicalization” of madness led to the pathologizing of behaviours and experiences that were previously considered within the realm of eccentricity or difference.

Julia Kristeva, a prominent French-Bulgarian psychoanalyst, philosopher, and literary critic made significant contributions to the understanding of mental illness, particularly from a psychoanalytic and literary perspective. While she has not specialized solely in the field of mental illness, her work has covered various aspects related to it. Kristeva’s work is deeply rooted in psychoanalysis, particularly the theories of Sigmund Freud and Jacques Lacan. She has used psychoanalytic concepts to explore the underlying psychological and emotional factors that contribute to mental illness. Her writings often delve into the unconscious and the ways in which repressed emotions and trauma can manifest as mental health issues. Kristeva’s work also focuses on the role of language and semiotics in understanding mental illness. She is known for her exploration of the symbolic order and the ways in which language and meaning-making can influence mental well-being. She has discussed the importance of language in expressing and understanding mental distress. Kristeva has written extensively on the concept of the “abject” and the “uncanny.” She suggests that encounters with the abject, which are experiences that provoke horror or disgust, can be deeply unsettling and have implications for mental health. Her work on the abject explores how individuals cope with experiences that challenge their understanding of self and reality. As a literary critic, Kristeva has analysed how literature and art can serve as a form of catharsis and a means of expressing and grappling with mental illness. She believes that creative works can provide insight into the

inner worlds of those who may be suffering from mental health issues. Kristeva has discussed the stigmatization of individuals with mental illness and the idea of “otherness.” She explores how society often marginalizes and stigmatizes those who deviate from the norm, and how this can exacerbate mental distress. Her work encourages empathy and understanding for those who are considered “other.” Kristeva’s concept of the “subject in process”<sup>2</sup> suggests that human identity is fluid and constantly evolving. This view challenges traditional, static notions of the self and can be relevant to understanding how individuals with mental illness navigate their identities and experiences. While Julia Kristeva’s work on mental illness is not the central focus of her extensive body of work, her psychoanalytical, semiotic, and literary perspectives provide valuable insights into the complex interplay between the psyche, language, and society in the context of mental health. Her contributions can be a valuable resource for understanding the intersection of psychoanalysis, literature, and mental health.

### **Telling afflicted lives: life-writing and fiction on physical disability and mental illness**

In this dissertation, my foray into the realm of literary disability studies and mental health scholarship is anchored in early twenty-first-century Indian life-writing and fiction. Paul John Eakin observes that, “ethics is the deep subject of autobiographical discourse. Writing about disability, then, not only involves the ethics of life-writing but of the ethics of living in a world of contingent relations” (Eakin 6). In the Introduction to the book, *Telling Lives in India: Biography, Autobiography, and Life History* (2004), David Arnold and Stuart Blackburn assert that

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<sup>2</sup> In “the Subject in Process”, Julia Kristeva “revisits Lacanian psychoanalytic theory in order to show “how the evolution of the subject is related to the evolution of language. According to Kristeva, the subject is by nature in motion, challenging the erroneous notion of the monolithic nature of language.””

life-writing can function as tools for individuals to make sense of their experiences through storytelling. However, these narratives are not created in isolation; they are influenced by cultural norms that shape and mould the way these stories are told. The very nature of life writing, tied to its unique context, means that it's subject to the influence of local social customs and literary traditions (12).

The exploration of life-writing concerning vulnerable human conditions spans back in time. In the Western tradition, the mid to the late twentieth century witnessed an influx of life writing and fiction authored by persons with chronic illnesses, mental health issues and physical disabilities, which evolved in tandem with the civil rights movements. For instance, breast cancer narratives such as *The Cancer Journals* (1980) by Audre Lorde and AIDS narratives such as Paul Monette's *Borrowed Time* (1988) and David Wojnarowicz's *Close to the Knives: A Memoir of Disintegration* (1991) emerged in conjunction with the women's liberation movement and the gay rights movement. There was a parallel growth in fiction around the same time on mental health conditions and physical disabilities such as Sylvia Plath's *The Bell Jar* (1963), Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962), Daniel Keyes' *Flowers for Algernon* (1966), John Steinbeck's *Of Mice and Men* (1937), Judith Guest's *Ordinary People* (1976) and Joanne Greenberg's *I Never Promised you a Rose Garden* (1964) amongst others. The disability rights movement and the psychiatric survivor's movement of the 1960s ignited an array of life-writing and fiction by individuals living with mentally and physically disabling conditions, aiming to convey their lived experiences through narratives. In the essay "Body Language: Illness, Disability, and Life-Writing" (2016), Thomas G. Couser introduces the term "auto-somatography" to describe "first- person narrative accounts of living with illness and disability" (77). In the book *Reconstructing Illness: Studies in Pathography* (1993), Anne Hunsaker Hawkins proposes a similar term, "pathography," to describe "first-person narrative accounts of patients striving to reclaim their bodies from the "social stigmatization and depersonalization of medical discourse"" (Hunsaker quoted in Purkayastha 44). In *The*

*Wounded Storyteller: Body, Illness, and Ethics* (1995), Arthur Frank further categorizes illness narratives into three distinct types: “restitution, quest, and chaos narratives” (49). Frank posits that “restitution narratives anticipate recovery and emphasize the curative aspect of the journey. In chaos narratives, illness appears as an unending ordeal with no respite or enlightening insights. Quest narratives revolve around the discovery that illness can be transformed into a means for the afflicted individual to undergo a profound personal transformation” (49). Frank presents these stories “as a form of testimony, asserting that the ill person is more than a survivor—she/he are a witness” (Frank quoted in Purkayastha 7). In essence, the confluence of literary disability studies and mental health scholarship within the framework of Indian life-writing and fiction underscores the intricate interplay between personal stories and broader societal contexts, revealing the power of narrative in shaping our understanding of health, illness, and human resilience. In the Introduction to the book, *Still Here: Memoirs of Trauma, Illness and Loss* (2019) Fiona Giles and Bunty Avieson, quote the observations of Chandler who opined that “designing and telling a life-story is purgative, reconstructive, integrative, transformative activity. The basic requirement of a narrative- pattern, structure, coherence, closure and balance- all engage a writer in creating a whole out of fragments of experience” (6). Giles and Avieson also propose that writers, as they engage in writing, should also create a scaffolding and depersonalize themselves from their personal afflictions, which becomes evident when they observe that, “this depends on the distance- crucially psychological but also geographical and temporal- from the trauma, and the therapeutic support and scaffolding that writers may construct around themselves as they write” (Giles and Avieson quoted in Purkayastha 6). As Pennebaker and Seagal argue in “Forming a story: the health benefits of narrative”-

the life-writing process allows one to organize and remember events in a coherent fashion while integrating thoughts and feelings... This gives individuals a sense of

predictability and control over their lives. Once an experience has structure and meaning, it would follow that the emotional effects of that experience are more manageable (124).

It would seem pertinent to suggest that life-writing, which potentially veer towards constructing a positive recovery narrative, provides a sense of agency, creativity and connectedness in the midst of the social anxieties. Paul Eakin in *How Our Lives Become Stories: Making Selves* (1999) stresses the link between narrative and identity with reference to memoirs and autobiographies: “Narrative is not merely a literary form but a mode of phenomenological and cognitive self-experience...” (100). Over the last three decades or so, there has been an upsurge in the publication of life-narratives of people living with illness and disability. Sharon L. Snyder and David T. Mitchell in “Disability Haunting in American Poetics” (2007), argue that “the characteristic intimacy with disabled characters in literature achieved through first-person narrative perspectives allows for a unique space for contemplating the physical and cognitive differences” (12). It is worth mentioning that there has been a wealth of narratives shared by people living with conditions such as autism, schizophrenia, Alzheimer’s disease and cerebral palsy that might be seen as factors that would rule out first-person narration. In able-bodied literary narratives, unreliable narration often stems from character flaws, personal biases, or subjective interpretations of events. This unreliability is usually attributed to the character’s psychology, motivations, or circumstances. In contrast, unreliable narration in disability and mental illness literary narratives can result from the disability or mental illness itself. The unreliability is rooted in the condition and how it affects the narrator’s perception of reality. It may include altered perceptions, memory gaps, hallucinations, or delusions arising from the condition. While the former is a deliberate literary device, in the latter, unreliable narration may still be a literary device but it may also foster empathy and understanding and can be a means of empowerment.

Before delving further into the concepts of embodied narratives and storytelling, it is important to draw a distinction between the body and embodiment. In everyday language, the term “body” is used to describe the material or physical structure of human beings whereas embodiment refers to the manifestation of an idea in its physical form. Abby Wilkerson defines embodiment as, “a way of thinking about bodily experience that is not engaged solely with the historical mistreatment of people either embodying physical disabilities or mental illnesses. It includes, pleasure, pain, suffering, sensorial and sensual engagements with the world, vulnerabilities, capabilities and constraints as they arise within specific times and places” (18). The common interpretation of embodied narratives pertains to the influence of the body and its sensory capacities on the creation, enhancement, or disruption of narratives. In simpler terms, the act of storytelling is deeply connected to the storyteller’s physical presence, significantly impacting how the narrative takes shape (Purkayastha 25). Lars Christer Hyden in his article, “Towards an embodied theory of narrative and storytelling” (2013), describes “narratives by people living with brain disorders as, “verbal actions” that engage people as both listeners and tellers, and as being enacted in specific situations” (228). Shibashish Purkayastha quotes the views of Hyden in his essay “Aesthetic Nervousness, Assuaging Distress: A review of select life-writing and fiction on physical disability and mental illness” thus:

Story-telling is a complex activity that engages both the teller’s and the listener’s abilities to use various kinds of semiotic resources (language, body parts), cognitive resources (memory, executive functions), as well as their coordinating abilities (monitoring), particularly for emotional and cognitive attunement. In order to understand these processes, not only must the story as text be in focus but also the actual physical and bodily activity of telling the story, including the use of all kinds of semiotic resources. (Hyden quoted in Purkayastha 28)

He further describes that “...human bodies, and the actions they are visibly performing, are situated within a consequential setting. The positioning, actions, and the orientation of the body in the environment are crucial to how participants understand what is happening and build

actions together” (Hyden 255). For Eleonor Antelius, “embodied narratives have the potential of establishing, confirming and negotiating shared worlds between the narrator and the reader” (Antelius quoted in Purkayastha 62). They suggest “not only the importance of the body in telling stories but also advancing why such embodied stories matter” (Antelius 62). Richard Menary in his article “Embodied Narratives” explains that “narratives arise directly from the lived experience of the embodied subject and these narratives can be embellished and reflected on if we need to find a meaningful form or structure in that sequence of experiences. In describing the sequence of events which culminated in me being hit on the arm by a hard cricket ball, I might construct a narrative around the sequence of perceptions and bodily actions that led to me being struck on the arm. I might think, narratively, about how I got into a position that allowed me to be so struck and how I might avoid it in future” (77). He further maintains that,

It is with our bodies that we perceive, act, experience and engage with the world and with others. If narrative is the ‘lens through which we filter our experience and plan for actions’ and develop an integrated conception of ourselves as persisting, temporally extended subjects, then a condition of possibility of this narrative is that we have an integrated, if not necessarily explicit, conception of ourselves as embodied agents. I call this conception a person’s bodily perspective. (Menary 111)

Menary and Hyden emphasize the significance of sense perceptions and experiences which assist individuals in articulating the ‘textured’ experience of the body, which I argue that the body in this context, serves as the locus for the creation of lived, embodied knowledge. Peter Brooks, a prominent narrative theorist has advanced theories of narrative desire, narrative time, and narrative ethics in *Reading for the Plot: Design and Intention in Narrative* (1984) which can be applied effectively to the study of life-writing and fiction on disability and mental illness. Analyzing the narrative desire in these texts can help scholars explore how individuals with physical disabilities or mental illnesses are motivated by the desire for empowerment,



understanding, and agency. It sheds light on their journey to overcome challenges and achieve a sense of closure or transformation. Readers' narrative desires are also significant. Examining how readers engage with these narratives, what they anticipate, and what resolutions or revelations they seek can offer insights into the impact of these stories on their perceptions and attitudes. Narrative time is an essential aspect of disability and mental illness narratives. These narratives often involve non-linear temporal structures, flashbacks, and flash-forwards to depict the progression of illness or disability, medical treatments, or emotional journeys. Analyzing the manipulation of narrative time can reveal how authors convey the evolving experiences of individuals living with disabilities or mental illnesses. It provides insights into the challenges, transformations, and coping mechanisms that unfold over time. Narrative time can also illustrate the cyclical nature of certain conditions, emphasizing the importance of long-term perspectives in understanding the lived experiences of individuals with disabilities and mental illnesses. Narrative ethics is particularly relevant in the study of disability and mental illness narratives. It involves considering the moral responsibilities of authors in representing these conditions and experiences accurately and sensitively. Additionally, the ethical engagement of readers with these narratives is significant. One can examine how readers respond to the ethical challenges presented in these texts, including issues of inclusion, empathy, and the portrayal of vulnerability.

### **Theoretical perspectives on disability, mental illness and literary studies**

This section attempts to provide a concise overview of the various theoretical approaches that have been instrumental in shaping this dissertation. During the 1970s, a number of influential scholars laid the foundation for the field of disability studies. Erving Goffman's theorisations on stigma and mental institutions and Foucault's *Madness and Civilization* (1961) have come

to the aid of scholars working at the intersections of disability, mental health and literary studies. According to sociologist Erving Goffman, the term ‘stigma’ describes the “situation of the individual who is disqualified from full social acceptance” (8). Analysing the subject from a historical standpoint, Goffman observes that “shifts have occurred in the kinds of disgrace that arouse concern” (10). In recent decades, there have been changes in the way certain aspects of stigma, as discussed by Goffman, are perceived. In his study, he classifies homosexuality as one of the categories of stigma. Another category discussed by Goffman is that of mental illnesses such as bipolar disorder, schizophrenia and post-traumatic stress disorder. Michel Foucault’s works like *The Birth of the Clinic* (1961), *Madness and Civilization* (1963), *Discipline and Punish* (1975), and *The History of Sexuality* (1976) posit how bodies are controlled, managed and disciplined within the structures of power and knowledge. Foucault’s theorisations of docile bodies, clinical gaze, madness, panopticism, archaeology of knowledge, episteme and bio- power have assisted scholars working at the intersections of disability, mental illness and literary studies. It is, however, in the 1990s that disability studies theorists begin to integrate Foucauldian notions of institutions, episteme and bio-power into the analyses of disabled people’s lives (Foucault quoted in Purkayastha 36). In the article, “What is biomedicine?” (2012) Cathy Lloyd observes that:

Modern Western Scientific medicine is often called “biomedicine” because it explains health in terms of biology. It attaches importance to learning about the body structure (anatomy) and systems (physiology) in particular to understand mechanisms like heart, arteries, nerve, brain and so on...So, a biomedical account is one which gives a physical and biological explanation for health and offers physical/biological method for ‘repairing’ bodies when they are not working properly. (15)

In the article, “Historiography of Biomedicine,” (2011) Ilana Lowy argues that biomedicine’s emergence in the mid-19th century was marked by doctors’ increasing reliance on laboratory

tests for disease diagnosis (117). While the primary focus of biomedicine<sup>3</sup> has traditionally been on the biological and physiological aspects of illness, it has also evolved to acknowledge and incorporate subjective domains related to illness and disability over time. In the early and mid-twentieth century, biomedicine was primarily concerned with establishing a scientific understanding of diseases. Emphasis was placed on identifying pathogens, developing vaccines, and discovering antibiotics. The focus was largely on objective, measurable factors associated with illness. Towards the latter part of the twentieth century, there was a growing recognition of the psychosocial dimensions of illness. The biopsychosocial model emerged, acknowledging the influence of psychological, social, and cultural factors on health and disease. Patient-centred care gained prominence, emphasizing the importance of considering patients' experiences, preferences, and values in medical decision-making. The late 20th century and early 21st century saw an increasing emphasis on patient advocacy and the incorporation of patient narratives into medical practice. The patient's subjective experience of illness became recognized as a valuable source of information for diagnosis and treatment. Narrative medicine, a field that focuses on the stories of illness, gained attention, encouraging healthcare professionals to listen to and understand the subjective aspects of their patients' experiences. With the advent of the 21st century, there has been a shift towards personalized medicine and genomics. While these advancements are rooted in biological understanding, they also raise ethical and subjective considerations. Issues related to informed consent, genetic counselling, and the psychological impact of genetic information on individuals and families have become integral to discussions in biomedicine. In the present day, there is a growing recognition of the impact of social determinants of health on illness and disability. Biomedical research and practice increasingly acknowledge the role of socio-economic factors, cultural

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<sup>3</sup> In Britain, the word biomedicine first appeared in Dorland's 1923 Medical dictionary, and meant "clinical medicine based on the principles of physiology and biochemistry. Keating and Cambrosio, op. cit., note 7 above, p. 52.

contexts, and systemic inequalities in shaping health outcomes. This broader perspective aligns with efforts to address health disparities and promote health equity. This evolution signifies a more holistic understanding of health that considers not only biological factors but also the individual, social, and cultural dimensions of illness experiences<sup>4</sup> (“Philosophy of Biomedicine”, Gaines, Kaplan, Moini et.al).

Although the biomedical model of disability and illness has made significant strides in the twenty-first century, there are authors and critics who opine those biomedical approaches to disability and illness even in its holistic form, can still be reductionist. It tends to focus on biological and physiological factors, sometimes overlooking the complex interplay of psychological, social, and cultural dimensions that shape the experience of illness and disability. The biomedical model often positions healthcare professionals as authorities in diagnosing and treating illness. Critics argue that this can perpetuate power imbalances, sidelining the voices and agency of individuals with disabilities or mental illnesses. Life-writing and fiction can be a platform to challenge these imbalances and assert the importance of patient perspectives. Labels, diagnoses, and medicalization can sometimes reinforce societal prejudices and stereotypes, which authors may critique in their works. Critics point out that the biomedical model, by its nature, tends to focus on pathology and dysfunction<sup>5</sup>. Life-writing and fiction provide an opportunity to explore and celebrate the strengths, resilience, and adaptive capacities of individuals with disabilities and mental illnesses, challenging a purely deficit-oriented perspective. Socioeconomic factors can significantly impact access to

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<sup>4</sup> “Philosophy of Biomedicine” (Stanford Encyclopaedia of Philosophy) <https://plato.stanford.edu/entries/biomedicine/>, “Legal and Ethical Aspects of Healthcare” by Jahangir Moini, “Socio-cultural construction of medical knowledge” by A.D Gaines, “Biomedicine” by Giora Kaplan, “Biomedical Sciences and Technology: History and Sociology” by A.Cambrosio.

<sup>5</sup> Critics like Lennard Davis, Tobin Siebers, Elizabeth Donaldson, Rosemarie Garland Thomson, Margaret Price, David Mitchell, Sharon Snyder, Nandini Ghosh, Anita Ghai, Githa Hariharan, Alok Aggarwal expressed their discomfort over biomedical model’s reliance on disability and mental illness pathology.

healthcare and the ability to fully participate in the recommended treatment plans. Critics argue that the biomedical model, even when holistic, may not always address the economic barriers that individuals with disabilities or mental illnesses face. The biomedical model often relies on standardized treatment protocols. Critics argue that these standardized approaches may not fully account for the uniqueness of each individual's experience and preferences, leading to a call for more personalized and patient-centred care. The influence of pharmaceutical companies on medical practices and the over-reliance on medication as a primary mode of intervention is one of the focal points of critique. Some argue that this approach may overshadow other forms of support and treatment that individuals may find beneficial. In essence, critiques of the biomedical model within life-writing and fiction often arise from a desire for a more inclusive, person-centred, and culturally sensitive approach to understanding and addressing illness and disability. These critiques contribute to ongoing conversations about the evolving nature of healthcare and the importance of incorporating diverse perspectives in shaping models of care.<sup>6</sup>

The term 'critical disability studies' as a critical school of thought emerged only in the latter decades of the twentieth century. The field of critical disability studies offers a critique of the medical model of disability, which tends to pathologize and medicalize disability, and instead emphasizes the social model of disability, highlighting how societal structures and attitudes play a significant role in disability. This perspective challenges the dominance of biomedical explanations and treatments and promotes a more inclusive and holistic approach to understanding and addressing disability. The emergence of critical disability studies as a field of enquiry can be attributed to a number of reasons. First, the social model of disability

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<sup>6</sup> *The Diving Bell and the Butterfly* by Jean Dominique Bauby, *Brain on Fire: My Month of Madness* by Susannah Cahalan, *The Noonday Demon: An Atlas of Depression* by Andrew Solomon, *Thinking in Pictures: My Life with Autism* by Temple Grandin, *An Unquiet Mind* by Kay Redfield Jamison are some of the writers who expressed their discomfort over biomedicine's obsessive reliance on pathology and the idea of repairing and mending the body.

argued for a distinction between “impairment” as a personal limitation and “disability” as a social parameter. Second, humanities scholars working within a postmodern perspective, argued for a decentring of subjectivity in the 1990s, in the USA. The third factor was the identification with queer, feminist and race theorists that dominant ideologies interlock to produce structures of oppression. Marian Corker, a British sociolinguist, feminist, deaf disability studies scholar, was at the forefront of the poststructuralist turn in disability studies. This theoretical methodology emphasizes on the interrogation of discourses and cultural meanings and the theorization of diversity. During the late 1990s, she began employing a poststructuralist critique to challenge dichotomous and binary modes of thinking and models of disability. She uses Derridean theories to deconstruct the dichotomous assumptions underlying the social model of disability — that is, individual and society, impairment and disability — and notes their hierarchical ordering and instability. Corker necessitates the need to look at literary and critical texts with the underlying assumption that fluidity and instability lies at the heart of identity formations and social relations when viewed from a poststructuralist framework. She argues for a dialogic relation between impairment and disability and is not in favour of privileging one over the other. Tanya Titchkosky and Rod Michalko in their essay “The Body as the Problem of Individuality: A Phenomenological Disability Studies Approach” (2017) begin by critiquing the biomedical worldview on disability as the “body-gone-wrong” and that body to be made worthy of living, should be treated in a way that makes it look and act normal (128). They quote Edmund Husserl’s observation that “the world surrounds us, and it is intuitively given to us. The world comes to us always configured as meaning – the world always means” (Husserl quoted in Titchkosky 129). A phenomenological account of bodily disorder discloses the emotional dimensions of physical dysfunction. In providing a window into lived experience, phenomenology provides insights about the everyday world of those who live with disabilities. It relies on theories of Edmund Husserl and Maurice Merleau-Ponty in

understanding the lived and embodied experiences of impairment. *Critical Theory and Disability: A Phenomenological Approach* (2015) by Teodor Mladenov is the first book which explores at length the phenomenological theories of Merleau-Ponty and Heidegger, to offer an understanding of the social phenomena surrounding the discursive object called “disability”, and to critically examine how other disability theorists have conceptualized this discursive construct. He raises questions about disabled people and sexuality, personal assistance and disabled people, discrimination, media representations of inaccessibility and disability, and the classification and assessment of disability in public policy, among other things. In order to understand mental illness, one needs to look at the various methodologies that have been used by the medical practitioners for therapy and also by humanities scholars and theorists. The anti-psychiatry movement of the 1960-70s is a well-known voice of opposition against the hegemonic discourse of psychiatry. The idea that mental disorders are closely tied to the problems of meaning and institutional dynamics was first relevant in the anti-psychiatry movement. Thomas Szasz opines that mental illnesses are “false substantives” concocted by modern psychiatry (95). Recent developments in postmodern thought attempt to reconstruct the opposition between the pathological and the normal, and the social and discursive forces that reproduces these domains. As Foucault observes in *Madness and Civilization* (1961):

The constitution of madness as a mental illness, at the end of the eighteenth century, affords the evidence of a broken dialogue... The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of such a silence. (xxi)

Postmodern studies have brought new kinds of analyses and critiques to bear on questions of self and subjectivity. Postmodern thought, among other things, examines the relationship between power, knowledge, and the self (Foucault 1977), its suspicion of self-justified meta-narratives (Lyotard 1984), and in its unstable, partial, and anti-totalizing view of language

(Derrida 1974). One of the important tenets of postmodernism is the undermining of 'totalizing knowledge' and Dwight Fee in the Introduction to his book *Pathology and the Postmodern: Mental Illness as Discourse and Experience* (1999) notes that texts such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), the central diagnostic text for psychiatric illness classification in the US (American Psychiatric Association, 1994) stand in isolation from the socio-political context. Such books are exemplary of the totalizing knowledge of psychiatry detached from the material realities. Fee further observes that health and pathology discourses tend to incorporate certain abstract systems of knowledge about self and living are incorporated in local environments (44). John P. Hewit and Michael Fraser in their essay "Is it me or is it Prozac? Antidepressants and the Construction of Self" (2000) analyses the effects of antidepressants on conceptions of self, and how discourses of psychopharmacology are being implicated in the social meanings of well-being and depression (111). Marxist scholar, Bruce Cohen working on mental health and illness, necessitates the need to contextualize their work in a set of historical and social power relations. Cohen opines that the sociologists of mental health set out to provide a Marxist analysis of the modern mental health system from Phillippe Pinel's classification of mental disorders in the eighteenth century to "drugs revolution" in the twentieth century. Cohen writes that Marx' theory of historical materialism has come to the aid of scholars working in this direction. He notes how mental disorders can be understood as, "fulfilling certain institutional and ideological prerogatives of industrial capitalism for compliant and productive workers" (Cohen). His book *Psychiatric Hegemony: A Marxist Theory of Mental Illness* (2016) is an influential work in this direction. A psychoanalytical approach to disability and mental health studies attempts to unearth how and why human subjectivity was deemed to be fundamentally different from the objective world of matter and bodies. The mind was an individual human freedom to be celebrated in contrast to the unruly body and the wild natural world. It posits a critique of Enlightenment rationalism and



Descartes' strict distinction of 'res-extensa' and 'res-cogitans' in his second *Meditations*. Dan Goodley in his essay "Jacques Lacan + Paul Hunt = Psychoanalytic Disability Studies" in the book *Disability and Social Theory: New Development and Directions* (2012) sees psychoanalysis as an Enlightenment project which played an important role in the construction of the self or the psyche. Lennard J Davis critiques Freud's works as a reductive binary creating the concepts of normal sexuality, normal function, and then contrasting them with the perverse, abnormal, pathological, and even criminal (8). Psychoanalysis and psychiatry are similar in the sense that they both share the goal of finding an effective treatment for human mental anguish. The foundation of psychiatry, however, lies with medicine and clinical research in finding ways to treat symptoms of illnesses such as hysteria. A psychoanalytical approach to mental illness is more concerned with determining unconscious causes of mental illness, and not merely the symptoms. As Saul McLeod observes,

The aim of psychoanalysis therapy is to release repressed emotions and experiences, i.e., make the unconscious conscious. Psychoanalytic psychologists see psychological problems as rooted in the unconscious mind and Treatment focuses on bringing the repressed conflict to consciousness, where the client can deal with it. (46)

Freud believed that determining and discussing causes is an effective treatment of mental illness. Psychoanalysis sees mental illness rooted in the unconscious rather than in the brain and central nervous system. Dan Goodley, in positing a critique of psychoanalysis and psychiatry as institutions, argues:

...the psyche can be understood as a cultural artefact of contemporary society that individualises social problems. Individual, medical, bio-psychological, traditional, charity and moral models of disability locate social problems in the heads and bodies – the psyches – of (disabled) people. This leads to the commonly held view that disabling society is not the problem: the disabled individual is... (181)

A post-structuralist approach to mental illness attempts to address and deconstruct dichotomous assumptions such as – sane/insane, sober behaviour/manic behaviour etc. One needs to look at the dialogic relationship of these categories instead of rigidly compartmentalizing them. A narrative theory paradigm is useful in understanding mental health and disability issues since it is based on a rejection of a unified self and considers developing models of social justice within mental health research. This approach enables the individual suffering from mental illness to author her/his stories and thereby exercise agency in bringing about a subjective transformation. Indian academic Anita Ghai offers insights on how theorists of Albert Memmi, Edward Said and Homi Bhabha– can come to the aid of postcolonial scholars and enrich the disability studies perspective. She opines that one needs to underscore the dialectic between coloniser (read ‘able subject’) and colonised (read ‘disabled subject’). Anita Ghai in her essay “Engaging with Disability with Post-Colonial Theory” (2012) contends that the creation of a devalued ‘other’ is a necessary precondition for the creation of the able-bodied rational subject who is the all-pervasive agency and sets the terms of the dialogue. Taking over from the portrait that he draws of the ‘other’ as it means to the colonizer, the colonized emerges as the image of everything that the colonizer is not (Ghai 273-4). She further observes that such a dichotomous understanding of disability is not tenable in a country like India since the lived reality of the disabled offer a far more complex picture. She necessitates the need to pay “attention to the contradictions and conflicts that can rise from their distinct historical and material relationships to class, religion, culture and patriarchy” (Ghai 274). Having briefly outlined the various theoretical approaches that have come to the aid of researchers working on mental health and disability issues, I now turn to discuss some of the seminal scholarships in the field of literary disability and mental health/mad studies.

Since I attempt to situate my dissertation within the broader corpus of the health humanities, medical humanities, literary disability and mad studies, firstly, I will attempt to

trace the origins, development and the various trajectories of disability and mental health and mad studies. Medical humanities is an evolving academic discipline, an interdisciplinary field of inquiry that draws on history, politics, literature, cultural studies, drama, bioethics, religion and explores their interrelationships. It combines the knowledge from all these fields and integrates it to medical practice. Its origins can be traced in the late 1960s, by a small group of people who shared a critique of medical education and a commitment to vigorous action to change it, by bringing lived experiences of patients to the aid of medical professionals. The disability rights movements in both the UK and the US have deep roots in the struggles of individuals with disabilities to gain recognition, rights, and societal acceptance. In the UK, the movement gained momentum in the mid-20th century, spurred by organizations like the National Spastics Society (now Scope) and activists like Barbara Lisicki. The emergence of the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s marked a turning point, as it challenged prevailing medical models of disability and advocated for the social model, emphasizing societal barriers over individual impairments. This shift laid the groundwork for campaigns and protests that demanded accessibility, equality, and an end to discrimination. The US disability rights movement also saw significant developments, particularly with the passage of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) in 1990. Activists like Ed Roberts, Judy Heumann, and Justin Dart Jr. played crucial roles, advocating for civil rights legislation and leading grassroots efforts to dismantle barriers to inclusion. Both movements continue to evolve, driven by the ongoing struggle for equal rights, accessibility, and societal change. The social model of disability, as developed by Michael Oliver and his colleagues in the Union of the Physically Impaired Against Segregation (UPIAS) in the 1970s, proposes a different understanding of disability than the traditional medical model. According to the social model, disability is not solely a result of an individual's impairment or medical condition, but rather arises from the barriers

and limitations imposed by society. These barriers can include physical, architectural, communication, and attitudinal barriers that prevent individuals with disabilities from fully participating in society on an equal basis with others. Oliver's work and advocacy were instrumental in shifting the focus of disability rights activism away from attempts to "fix" individual impairments and towards efforts to address and remove societal barriers. His contributions have had a profound impact on the disability rights movement, both in the UK and internationally, and continue to shape policy and advocacy efforts aimed at promoting inclusion, accessibility, and equality for people with disabilities. Medical humanities, as a discipline, is mainly concerned with training medical practitioners with knowledge from various other disciplines. It stands in contrast to the health humanities, which links health and social care disciplines to the arts and humanities. In 1967, the Pennsylvania State College of Medicine established the first Department of Humanities in a U.S. medical university. Meanwhile, in the UK, there was a push to reintroduce medical ethics into MD education, with organizations like the London Medical Group playing a role (Shotter et al., 2013). Several factors converged to bring the humanities back into medicine at that time. Edmund Pellegrino's essay "The Hippocratic Ethic Revisited," (1973) can be seen as a manifesto for the medical humanities. Pellegrino argued that the complexities of modern life necessitated a fresh examination of medical ethics and the importance of humanistic medical training. Pellegrino played a pioneering role in the development of medical humanities. He led the Society for Health and Human Values at Texas University, where he articulated a vision for the field (Engelhardt, 1990). In 1976, he founded the *Journal of Medicine and Philosophy*, fostering scholarly debate and the establishment of disciplinary standards and issues. Subsequently, the *Journal of Medical Humanities* emerged in 1979, marking a significant expansion of the health

humanities in the United States.<sup>7</sup> Health humanities, on the other hand, refers to the application of the creative arts and fine arts and the humanities disciplines such as literary studies, philosophy, law and religion to discuss promoting human health and well-being. In the health humanities, health is understood based on dialogical and multiple truths in contrast to the monolingual truth of scientific inquiry. The domain of health humanities seeks to merge the fields of the medical humanities as well as fields such as arts and health, therapies, community arts to work more synergistically to advance creative public health. It has brought diverse academics, social care and education professionals to work with the public and find newer applications through the arts and the humanities in an interdisciplinary and non-hierarchical way.<sup>8</sup> Thus, the field of health humanities does not solely focus on medical notions of health and well-being. As Crawford and Brown write, the health humanities offer a “superordinate evolution” that advances innovation, mutuality, and dialogue between congruent traditions. In this way, it seeks to inspire, not to control or govern innovation” (41). In 1977, George Engel’s influential article in *Science*, “The Need for a New Medical Model: a Challenge for Biomedicine,” was part of a broader educational reform movement nationwide. The University of Rochester, in 1984, became one of the early medical schools to establish a dedicated Department of the health humanities. Founded by Dr. Robert Joynt, a neurologist and then Dean of the Medical School, along with Dr. Jules Cohen, an internist and Senior Associate Dean of Medical Education, this department emerged as an extension of the school’s biopsychosocial model. They attempted to integrate humanities into the medical curriculum by applying humanities’ approaches to the study of medicine and healthcare. Kathryn

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<sup>7</sup> See “The Long History of the Medical Humanities” <https://thepolyphony.org/2022/07/07/the-long-history-of-the-medical-humanities/#:~:text=In%201976%20he%20founded%20the,humanities%20in%20the%20United%20States.>

<sup>8</sup> See Paul Crawford’s “Introduction: Global health humanities and the rise of creative public health” in *The Routledge Companion to the Health Humanities*, Routledge, 2020.

Montgomery, a PhD in English Literature, served as the department's first Director.<sup>9</sup> The earliest description and definition for the health humanities, a term previously only loosely used, was used in a paper presented at the Economic and Social Research Council Business Seminar held at BioCity Nottingham, United Kingdom in 2007 (Crawford 2007). The health humanities adopt an interdisciplinary, intersectional and activist approach to the arts and the humanities in informing and transforming health care. It is a field “engaging with the contributions of those marginalized from the medical humanities” (Crawford et.al, 2010). Health humanities does not merely concern itself with training health professionals through the arts and the humanities, or a privileging of a medical, biomedical, or scientific frame over the expertise of the public or non-science and non-medical contributions, and problematizes the mechanistic and reductive notions to injecting the arts and the humanities as a kind of treatment.<sup>10</sup> The field of Literary disability studies and mental health studies has been advanced by scholars who engage with disability studies and mental health studies with a focus on literary representation, literary theory and criticism that tends to deconstruct normative assumptions about the able body and mind. Narrative medicine as a methodology in medical practice brings under its purview the importance of the material realities of patients. The field of narrative medicine grew out of the work of physician Rita Charon who formally defined “narrative medicine” as medicine practiced with “narrative competence”, that is, “competence to recognize, interpret, and be moved to action by the predicaments of others” (6). Elsewhere, Charon describes narrative medicine more simply as “medicine practiced by someone who knows what to do with stories” (7). Training of medical professionals in this field teaches the application of literary theory and creative writing skills to the situations and interactions in

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<sup>9</sup> See Health Humanities and Bioethics. <https://www.urmc.rochester.edu/medical-humanities/about-us/about.aspx>

<sup>10</sup> See Paul Crawford's “Introduction: Global health humanities and the rise of creative public health” in *The Routledge Companion to the Health Humanities*, Routledge, 2020.

medical research. To this purpose, the narrative medicine program directed by Charon at Columbia University trains participants in “close reading, attentive listening, reflective writing, and bearing witness to suffering” (7). Narrative medicine advances an empathetic understanding and accountability of the narratives of the afflicted. Rita Charon’s theory of narrative medicine can be useful in studying literary narratives of disability and mental illness because it provides a framework for understanding and analyzing how individuals with disabilities or mental illnesses use narrative to express their experiences, challenges, and perspectives. Narrative medicine emphasizes the importance of empathy and understanding in healthcare. Similarly, when studying literary narratives of disability and mental illness, it’s crucial to empathize with the characters or real-life individuals portrayed in these narratives. Understanding their experiences and struggles can help one to gain insights into the lived experiences of people with disabilities and mental illnesses. In narrative medicine, the patient’s narrative is at the centre of care. Analyzing these narratives from a patient-centered perspective can shed light on their unique experiences, challenges, and coping mechanisms. Narrative medicine stresses the importance of effective communication between healthcare professionals and patients. By analyzing the language, symbolism, and narrative techniques used in these texts can provide insights into how these experiences are expressed and understood. Rita Charon’s approach also emphasizes the ethical aspects of patient care. When studying literary narratives, it’s important to consider the ethical implications of how disability and mental illness are portrayed.

### **Literary Disability studies, Mad studies, mental illness and literary studies.**

Disability studies emerged out of the disability civil rights movement in the 1960s. Some of the seminal voices behind the emergence of the disability rights movement in America were

Dr. Timothy Nugent, Edward Verne Roberts and Frank Bowe. Early scholarship in this field distinguishes the medical model of disability, which locates physical and mental impairments in individual bodies, from the social model, which understands the social barriers aggravate the conditions of the disabled people. The social model names both architectural and attitudinal barriers as the cause of disablement. Over the last few decades, the field has expanded to include individuals with a wide range of disabilities—not just physical conditions, but also mental and chronic ones. However, the foundational phase of Literary Disability Studies began in 1995 with the publication of Lennard Davis’ monograph, *Enforcing Normalcy: Disability, Deafness and the Body* which was followed by Rosemarie Garland Thomson’s *Extraordinary Bodies: Physical Disability in American Literature and Culture* in 1997. Davis in his monograph shows how disability concerns are foundational to any critical analysis. In the book’s preface, Davis refers to a discussion he had with a colleague who uses a wheelchair as they planned a disability session for the Marxist Scholars Conference in New York in 1994. Davis had noticed the greater popularity of sessions on topics like the novel or the body at professional conferences. His colleague explained that “people don’t come to sessions on disability. They think it is a specialized area and only the disabled come” (xii). He seems to suggest that knowledge of disability was rare until then. Warren G. Harding popularized the term “normalcy” during his 1920 US Presidential election. Lennard G. Davis and Rosemarie G. Thomson, in their Introduction, describes two terms- “normalcy” (Davis) and “normate” (Thomson) – in definitions of disability. As both showed, these are ideological constructions which tended to disavow any form of deviations from a set standard. Ableism thus took its place alongside homophobia, sexism, racism, patriarchy and colonialism. Lennard Davis examines the historical context in which the ‘normal’ emerged. He traces its genealogy to the rise of statistics and eugenics in the nineteenth century. At this time, the idea of the “average citizen” became central to national discourses. For Davis, “normalcy” or “the normal body”



was based on the idea of “the average man” which tends to erase all differences among individuals in the society. He writes that, “the very structures on which the novel rests tend to be normative, ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her” (11). Along a similar vein, Garland-Thomson uses the term “normate” to describe those who are unmarked by the stigmas of disability, framing disability as a minority (rather than medical) discourse. The word “normate” highlights assumptions about the body in politics, films, literature, and other areas, including the erasure of cultural and bodily difference. David Mitchell and Sharon Snyder’s book *Narrative Prosthesis: Disability and the Dependencies of Discourse* appeared in 2000 which unpacked notions of how ableism features in narrative. The key term “narrative prosthesis” outlined how texts rely on disability to make narratives work. The term meant that disability has been used throughout history as, “a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight” (49). To establish this literary understanding, they discuss some of the bodily representations in literature in which, “the body’s weighty materiality functions as a textual and cultural other— an object with its own undisciplined language that exceeds the text’s ability to control it” linking the ineffectuality of language to understand materiality (223). They think that disability in literature and film is generally used as a metaphor to convey something about a character. Their primary concern seems to be literary representations’ inability to convey the materiality of disabled experiences. For example, Benjy in *The Sound and the Fury* (1929) has a cognitive disability, but many critics argue he is sometimes reduced to a “moral arbiter for the rest of the characters” (Bérubé 575), a standard on which the reader’s judgements about the character might be based. Tanya Titchkosky in her book *Disability, Self, and Society* (2003) shares her experience of living with dyslexia and the blindness of her partner, Rod Michalko. Incorporating their lived narratives, she tries to examine the societal and self-inflicted barriers

imposed on oneself. The author interprets both disability and people with disabilities with the physical environment and writes, “physical and social environment is exclusionary” (97). In the fourth chapter of her book, “The Expected and the Unexpected”, the author cites an example of her university campus experience: “it is usual to groan while opening the heavy entrance doors of the Sociology department building” (Titchkosky and Michalko 71). She refers to this struggle with the doors as a public announcement that this environment is suitable only for a person who has the ability to move easily, as well the strength necessary to secure entrance to the building. The author experiences this physical and social environment as an exclusionary state for people with disabilities. Later on, Tobin Siebers in *Disability Aesthetics* (2010) and Ato Quayson in *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007) underscore the importance of the disabled body in literary representation. Ato Quayson observes a “dissonance” or “nervousness” at the level of the form itself when disability enters the narrative. In his Introduction, Quayson defines “Aesthetic Nervousness” as the short-circuiting of the dominant protocols of representation of a text when it encounters a disabled character. This crisis works in several ways, according to Quayson. Firstly, on questions surrounding representing a disabled character, Secondly, will that character or disability itself ever be able to be represented except as a metaphor for some aspect of the human condition? The final part is the crisis of reading, in which readers will find that the disabled character poses problems for aesthetic reception. In all cases, what is triggered is what Quayson calls “aesthetic nervousness.” He sees this as an oscillation between the domains of the aesthetic, the ethical, and the sociocultural, often resulting in a kind of “metaphysical as well as textual impasse” (29). Tobin Siebers in his essay “Disability Studies and the Future of Identity Politics” (2017) observes that in order to challenge “the ideology of ability” that permeate contemporary society, we need to develop a “theory of complex embodiment”. This focuses on the reality of the lived experiences in relation to the afflicted and suffering body. In the book, *Disability*

*Rights and Wrongs* (2006) Tom Shakespeare argues for the adoption of a social model of disability, emphasizing the role of societal barriers and discrimination in disabling individuals. This book offers a sociological perspective on the political dimensions of disability. Emily Russell's *Reading Embodied Citizenship: Disability, Narrative and the Body Politic* (2011) examine a wide array of literary works ranging from the times of Mark Twain to David Foster Wallace. Russell underscores the importance of envisioning the relationship between textual, social and physical bodies in imagining American democracy. In her Introduction to the book, she expresses her discontent at the use of disabled bodies as metaphors. She contends that nation-states marginalize people with disabilities. Russell develops the embodied site of the disabled as a material and discursive place capable of destabilizing the regulations of oppressive ideologies. She discusses other discursively constructed sites of the crippled and the grotesque. She argues that this body "carries the burden" of both its materiality and its abstractions—textual, symbolic and social (96). This disabled body is not "essential". It is a richly confused, multiply articulated, contested site, precisely the place out of which might be produced a powerful politics and a speaking activism. (102) Russell opines that "embodiment is a mutable discursive and material category shaped by the reading practices of a no less dynamic social body" (198). She elaborates on the various regulatory codes that restrict thought at the regulated site of disability: the body foreclosed and rigidified into a sight—a spectacular curiosity, a site that generates "the simultaneous need to stare and to look away" (103). But this site of the disabled body is not static; it is a dynamic process—more complex and slippery than the simple medicalized disabled body. Clare Barker's *Postcolonial Fiction and Disability* (2012) is the first scholarly examination of how disability is portrayed in the literature of postcolonial nations. Barker analyzes five texts from postcolonial countries: *Potiki* (1986) by Patricia Grace, *Midnight's Children* (1981) by Salman Rushdie, *Nervous Conditions* (1988) by Tsitsi Dangarembga, *Cracking India* (1988) by Bapsi Sidhwa, and *The Famished Road* (1991)

by Ben Okri. In her introductory remarks, Barker emphasizes the importance of disability studies scholars looking beyond Western literature to explore literary works from postcolonial regions. Barker suggests that colonialism has inflicted lasting physical and mental damage on these nations, which have often been depicted as childlike and primitive by Western perspectives. Unlike some disability studies scholars who find the use of disability as a metaphor problematic, Barker argues in favour of “narrative prosthesis” within the context of postcolonial literature. She contends that when disability metaphors are used in these narratives, they are not merely superficial devices but instead emerge naturally from the authors’ postcolonial concerns, often stemming from the real circumstances of these societies. In two of her seminal works- *Disability and Modern Fiction* (2011) and *Literature and Disability* (2015) Alice Hall introduces the readers to the field of literary disability studies through various thematic explorations of disability and impairment in literary works. In the “Introduction” to *Disability and Modern Fiction*, Hall quotes Derek Attridge, Sharon Snyder and David Mitchell’s views on the capability of literary works to take us through an intense experience of the interior lives of these characters (5). Hall further asserts the centrality of literary studies in understanding the aesthetic and ethical challenges implicit in the disabled body. (9) She notes that until the 1960s the role of “affect”, which was an inescapable emotional and ethical dimension to any representation of disability, was ignored in literary representations of the disabled. It was only with the emergence of the civil rights movement such as women’s liberation, gay rights and black civil rights movements in this period provided shared, alternative models for understanding identity and more politicized modes of reading (or re-reading) texts (15). She pleads for a more empathetic representation of the disabled characters. Alice Hall in her essay “Disability Life Writing” (2015) opines that there has been a boom in life writing in which writings by ordinary people, rather than renowned public figures, have been written, marketed and consumed recently. New vocabularies have emerged such as

“autosomatography”, “autie-biography” and disparaging labels such as “misery literature” and “nobody memoir” (Thomas Couser’s terms in *Signifying Bodies* (2009)) in this regard. Hall ascribes the reason behind this to “the growing accessibility and decreasing costs of self-publishing technologies have extended the reach of disability life writing and significantly widened its definition, arguably to incorporate new condensed forms such as the blog post, tweet, or the newsfeed” (130). Hall notices a radical change from “under-representation” to “hyper-representation” in the last twenty-five years or so. She explains that, this necessitates a thinking of literary forms and disability representations in the way they draw attention to, the nuances of language, genre and narrative perspective, but also because thinking through the reciprocal relationship between literature and life writing can help us to question and to complicate claims about authenticity, objectivity and the web of cultural associations and narrative conventions through which both life writing and literary works are constructed” (130). In the process, Hall writes, “debates about empathy, identification and imagination are enriched” (130). Hall further opines that there has been spurge of “coming out” narratives pertaining to disability and mental illness. These narratives suggest a shift from the interior to the public. The disability and mad pride activists borrow this term from lesbian and gay activism. The need to “come out” is oppressing because the individual is required to account for his/her disability and mental illness in a way a able-bodied/mind person would not be expected to do. Elizabeth Brewer makes a similar claim in her essay “Coming Out Mad, Coming Out Disabled” (2018), where she argues “for disclosure as a form of community building” (12).

The psychiatric survivor’s movement (peer/consumer/survivor/ex-patient movement) emerged as a direct outcome of the civil rights movement of the 1960s and 1970s and the personal accounts of psychiatric abuse endured by former patients. Elizabeth Packard and Judi Chamberlin are some of the early voices. The primary idea behind the inception of this

movement is challenging the authority of psychiatry. However, the field of Mad studies as an academic discipline is still in its early stages and is typically associated with Canadian Mad scholarship and activism. Brenda A. LeFrancois coined the term “Mad Studies”. The impetus for this field can be traced back to the Madness, Citizenship and Social Justice Conference held in British Columbia, Canada in June 2008. This event underscored the need for developing a critical area of study focused on the exploring the complexities of madness in literature and culture. A significant milestone in this direction was the publication of *Mad Matters: A Critical Reader* in Canadian Mad Studies in 2013. However, it’s important to note that the history of Mad scholarship dates back to the 1960s emerging in parallel with the mad liberation movement and the disability rights movements in the same period. Elizabeth Donaldson writes that, “the birth of the Mad movement is inspired by the gay liberation movement as well as the black civil rights movement. Mad Studies is multidisciplinary – drawing on social sciences, humanities and cultural studies. In addition, like disability studies, it has been heavily influenced by the concept of “intersectionality”– the importance of seeing “mad oppression” as being inseparable from other social dimensions such as gender, ethnicity, social class, age, and disability.” (Donaldson 33). The one book in critical theory which laid the groundwork for theorists working in this field can be attributed to Michel Foucault’s *Madness and Civilization* (1961). It provides a comprehensive account of the representation of the “madmen” in Western history, through the classical age to the development of modern psychiatry. Foucault explores “how mental illness is seen and treated. The birth of the asylum and the gathering of the insane provided new directions in the development of psychology” (23). The key to understanding the medieval conception of Madness, to Foucault, is abandonment. He tells us soon after leprosy disappeared, poor vagabonds and criminals would take the place of the mentally deranged. Foucault suggests that, in the 17th and the 18th centuries, the perception of madness saw a complete change. With the advent of the Enlightenment, knowledge and power of reasoning

were consolidating grounds and madness was driven into the domains of irrationality. Foucault calls this era the era of isolation of the madmen from sanity. During this age, with the advent of industrialization, there was the structuring of the asylum, which reflected the values of the bourgeois society. Towards the end of the eighteenth century, any facility holding a mentally ill person required to produce a certificate. Doctors played an important role in these institutions, and this was where the modern practice of psychiatry blossomed. In the same year appeared Erving Goffman's *Asylums: Essays on the Social Situations of Mental Patients and other Inmates* (1961). This book is the result of the author's field research conducted at St. Elizabeth's Hospital in Washington D.C. In the Introduction, Goffman describes the mental hospital as a "total institution," where strict rules and regulations govern every aspect of daily life. Patients are deprived of the fundamental forms of self-expression" (12). Instead of fostering recovery, such conditions lead to the development of disordered behaviours, which ironically are the reasons for which these individuals are initially admitted in the first place. In one of his essays, "The Insanity of Place", Goffman drew a parallel between asylums and concentration camps and boarding schools. In his introduction, Goffman expresses his disparaging attitude towards psychiatrists who, "outwardly maintain the fiction that they are running a 'hospital' for the benefit of 'patients' who have come for 'treatment'" (23). Approximately twenty years later, a detailed examination of madness as a recurring theme in literary representations was explored by Lillian Feder's *Madness in Literature* which was published in 1980. In the Introduction, Professor Feder tries to trace, "not a history of madness in literature but is a study of representative literary explorations of the deranged mind" (xv). In his essay, "Psychiatric Power" (1994), Foucault observes that "power is not something that is possessed; it is rather dispersion, relays, networks, reciprocal supports" (4). He further states that, "power is also rife with struggle, war, tactics, strategies and microphysics of disciplinary power" (Foucault 16). And, "this notion of struggle will permeate the relation between psychiatrist and

patient, and run right through the asylum; before the problem being one of knowledge, or rather, for the problem to be able to be one of knowledge, of the truth of the illness, and of its cure, it must first of all be one of victory. So, what is organized in the asylum is actually a battlefield” (Foucault 16-17). In *Madness, Distress and the Politics of Disablement* (2015), Helen Spandler and Jill Anderson raise questions pertinent to both disability studies and mad studies scholarship in the Introduction. This anthology brings together scholars and activists from Europe, Australia, North America and India to explore the relationship between madness, distress and disability. They raise questions such as “what are the consequences, for someone experiencing madness or distress, of being categorised as a disabled person? what are the benefits and limitations of adopting a disabled identity? can disability policies benefit people with mental health problems (and what are some of the barriers preventing them from doing so)? Can the social model of disability apply to madness and distress (and if so, how)? how much can the mental health service user/survivor movement learn from the disabled people’s movement, and vice versa? how do mad studies and disability studies connect, if at all? how can disabled people and mental health service users and survivors work together and form alliances to advance our collective interests?” (2). In the same Introduction, Liz Sayce (2000) examined different approaches to “overcoming discrimination and social exclusion in mental health and concluded that the social model offers the best possibility of making progress. She argues that a ‘disability inclusion’ model would help people develop a positive identity, rejecting shame as something imposed by others, while also providing rights by giving individuals recourse to the law through anti-discrimination legislation” (3). Elizabeth J Donaldson’s *Literature of Madness: Disability Studies and Mental Health* (2018) brings together scholars working in disability studies, mad studies and post-colonial theory together. In one of the essays in the volume, “Coming Out Mad and Disabled”, Elizabeth Brewer begins by stating that disability studies scholars have come to recognize psychiatric disability as an



object of study only recently. In 2013, *Disability Studies Quarterly* published a special issue- “Disability and Madness” and mad studies emerged as a critical field of enquiry in 2008, which has its roots in psychiatric survivor activism. This field owes its origin to the publication of Judi Chamberlin’s testimony *On Our Own* (1977) which lays bare the indignities and abuses, she had to face at the hand of psychiatry. In her essay, Brewer points to the paucity of intersectional critical work on disability and mental illness. She argues that claiming both mentally ill and disabled identities, “increases the authors’ credibility and allows the writers to powerfully critique scholarship and activism related to mad and disabled people’s rights” (13). Both disability and mental health studies take as their critique, the pathologizing of human difference. Srikanth Mallavarapu’s chapter in the same anthology- “Resistance, Suffering and Psychiatric Disability in Jerry Pinto and Amandeep Sandhu” examines their works as important instances in the Indian context of mental health and illness. Mallavarapu explores the lived experience of schizophrenia in the novels of Pinto and Sandhu within the framework of Arthur Kleinman’s model of resistance and suffering, specifically in the Indian context.

#### **A brief overview of the Indian scholarship on disability and mental illness.**

Nilika Mehrotra traces the historical development of the disability rights movement in India by examining the social and political circumstances that gave rise to it. This movement came into existence relatively late, in the 1990s, and was fostered by the influence of women’s movements and the support of international agencies, creating a favourable environment for its emergence in India (Mehrotra quoted in Purkayastha 22). In the book *Gendering Mental Health* (2015), Renu Addlakha and Bhargavi Davar describe reasons such as domestic violence, sexual abuse and regional conflicts which exacerbate mental health issues. They assert that “most funding towards mental health is utilized for institutional care that focuses on addressing solely

biological vulnerabilities rather than social stressors (such as poverty, employment status, abuse, homelessness)” (Addlakha and Davar 23). Researchers and advocates on disability such as Addlakha, Ghai and Ghosh note that “there has been a shift in the understanding of disability from locating the ailment in the body to various social parameters which inflame the experience of living with disabilities” (quoted in Purkayastha 28). Regarding the current scenario of mental health in India, Davar, Addlakha et.al observe that “in India, health care professionals and people need to acknowledge that mental health issues are as intrinsic to human well-being as physical health issues” (11). Nandini Ghosh’s *Interrogating Disability in India* (2017) is a compilation of eleven essays by scholars from divergent fields (sociology, political science, law, economics, history). In the Introduction, Ghosh necessitates “the need to conceptualize the concept of “disability” with other parameters such as religion, gender, caste and class. She begins by stating that the medical definition of disability which stresses the limitations of functioning, came to be as a result of the world wars” (5). She observes that “there is a power play between the doctor and the disabled person or the patient, who is ascribed a clinical label and sought to be normalized through preventive or curative medical technology. Such clinical definitions of disability also become administrative tags for controlling disabled people’s access to financial and other assistance as well as attaching a stigma to the labelled person by suggesting a physical imperfection or deviance from the norm” (Ghosh 3). The medical model overlooks the challenging environments that exacerbate the difficulties faced by disabled individuals. It tends to reduce life to a medical context, emphasizing biological and physiological limitations while failing to recognize the societal obstacles that play a significant role. In contrast, the social model, although valuable, sometimes neglects the actual lived experiences and practical challenges of disabled individuals. Anita Ghai’s *Rethinking Disability in India* (2017) positions disability activism within the framework of struggles with other structures of oppression in India. In her essay “Engaging with Disability with Post-

Colonial Theory” (2012), Ghai contends that “the creation of a devalued ‘other’ is a necessary precondition for the creation of the able-bodied rational subject who is the all-pervasive agency and sets the terms of the dialogue. Taking over from the portrait that he draws of the ‘other’ as it means to the colonizer, the colonized emerges as the image of everything that the colonizer is not” (Ghai 273-4). She further asserts that “such a dichotomous understanding of disability is not tenable in a country like India, since the lived reality of the disabled offer a far more complex picture. She necessitates the need to pay “attention to the contradictions and conflicts that can arise from their distinct historical and material relationships to class, religion, culture and patriarchy”” (Ghai 274). In the field of mental health research, Renu Addlakha and Bhargavi Davar’s works have garnered some critical attention. In India, mental illness has largely been seen through a biomedical lens wherein a person with mental illness needs to be diagnosed and treated with medication accordingly. The socio-cultural implications of mental illness have largely been ignored. Renu Addlakha’s book *Deconstructing Mental Illness: An Ethnography of Psychiatry, Women and the Family* (2008), is a critical ethnographic field survey which brings to the fore lived experiences of women living with mental illnesses. In the Introduction and the first chapter to her book, she describes that the medical model looms large in mental health practice where psychiatric institutions take precedence over the patient’s lived experiences. This had its origins in the eighteenth century with the emergence of biomedicine as a field of study. This was precisely the time when the disease model of human behaviour came to dominate discourses of medicine (55-56). Bhargavi V. Davar in her essay “The Norms and Etiquettes of ‘Having’ a Mental Illness” describes the observations of Andrew and Digby that, “the asylum practice is indicative of societal practices of labelling and marginalization, leading up to a demand for spaces where people can be put away in confinement” (3). She seems to suggest that the embodied subjects are placed within a hierarchy of definable physical and mental traits that tend to determine the position of hierarchy, status and power. Bhargavi

Davar and T.K Sundari Ravindran's edited volume *Gendering Mental Health: knowledges, identities and institutions* (2015) is a compilation of nine essays by researchers and survivors on mental health issues. In the Introduction, Davar asserts that "the purpose of this book shall be to explore the state of mental health of Indian women, with respect to social attitudes, cultural barriers, treatment policies, safeguards, or lack thereof" (x). In her essay, "Identity Constructions for 'Mentally Disturbed' Women: Identities Versus Institutions" (2015), Bhargavi Davar raises some pertinent questions regarding mental health and narrativity when she argues whether "people living with a mental ailment have a 'memory' or the 'insight' to tell their own stories" (196). She examines "the roles of institutions (office, family, school, hospitals etc) in developing one's identity. She focuses on women's voices and examines the role of families in creating childhood depressions and highlights the trauma created through treatments" (Davar 197).

**Literary scholarship on selfhood and agency in life-writing and fiction on physical disability and mental illness**

This section tries to provide an overview of select literary scholarship in the field of selfhood and agency in relation to physical disability and mental illness. In this dissertation, it is essential to clarify that while the exploration revolves around how Indian authors negotiate and re-narrate definitions of disability and mental illness, it will primarily employ medical definitions of these terms as a foundational framework. However, it is imperative to approach these medical definitions with caution, recognizing their limitations and potential biases. The overarching aim is not to solely rely on medical perspectives but rather to critically analyze how Indian authors engage with, challenge, and reshape these definitions within the cultural and societal contexts of India. By emphasizing this nuanced approach, the dissertation seeks to

illuminate the complexities inherent in discussions surrounding disability and mental illness within Indian literature and society. Katrina Anne Longhurst's PhD dissertation "Critical Strategies of Narrating Mental Illness in Contemporary Life Writing" (2019) examines modern autobiographical works that address mental illness, with a particular focus on those published in the UK and USA. Her research centres on memoirs that break away from the conventional narratives of triumph and personal quests commonly found in contemporary culture and academic discussions. She employs a feminist approach and draws upon theoretical perspectives from critical medical humanities, disability studies, trauma studies, and autobiographical studies. Her work delves into the connections between mental illness and experiences of sexual violence, while also exploring concepts of relationality, intersectionality, and interdependence. According to Longhurst, the authors in these memoirs use ideas of ambiguity, entanglement, polyvocality, and hybridity to convey their personal experiences with mental illness. She believes that these open-ended narratives offer valuable insights into the ongoing complexities of living with mental illness. I take Longhurst's cue to examine the lived experiences of physical disability and mental illness in Indian life-writing and fiction and how the selected texts describe the entanglements of disability, mental illness with parameters of identity such as class, gender, and family. Hanna Meretoja's lecture on "Narrative Agency, Life Writing and Mental Illness" (2020) has been useful to my research project as she clearly lays down the three pivotal analytical frameworks for narrative agency namely "narrative awareness, narrative imagination and narrative dialogicality" (Meretoja). She argues in favour of the dialogic role narrative plays in showcasing its self-reflexivity and metanarrativity, not only about its status as a narrative but also on what constitutes narrative sense-making. Similarly in her book, *The Ethics of Storytelling* (2018), Hanna Meretoja proposes "an approach pertaining to how interpretation takes place when people engage in the act of storytelling, either as storyteller or as audience. This is what she calls 'narrative hermeneutics'"

(6). According to Meretoja, “reading, listening to, watching a story is seen as an act of meaning making, always leading to numerous interpretations” (7). She holds the view that storytelling is itself an interpretive act as she writes, “narrative [is] a culturally mediated interpretive practice that makes someone’s experiences in a particular situation intelligible by drawing meaningful connections between them” (Meretoja 7). This can help us understand the relationship between narrative and experience, as storytelling is “a way of making sense of our being in the world” (Meretoja 7). Philip Max Neilsen and Ffion Murphy in “The Potential Role of Life-writing Therapy in Facilitating ‘Recovery’ for those with Mental Illness” (2008) note that “Life-story or life- writing can be understood in this context as involving more than disclosure or oral expression of a subject’s ‘story’ as in psycho-therapy – life-story is understood as a written, structured narrative” (11). They further note that-

Life-writing is simply telling a story from your life and perhaps musing or commenting on it at the same time. When you write a short account of something chosen from your life, you are making a pattern, using your memory, using your powers of description – you are being creative. You are being a story-teller. And story-telling is one very important thing that makes us humans different from all other animals – and it is a way in which we find a lot of meaning in our lives. (Neilsen and Murphy 12)

Dorthe Kirkegaard Thomsen, Tine Holm and others in the book *Storying Mental Illness and Personal Recovery* (2023) delve into multiple user recovery narratives, offering valuable perspectives on mental illness that go beyond the scope of conventional medical and psychological research. These narratives illuminate the diverse and multifaceted nature of the subjective experience of mental illness, shedding light on how individuals with mental health challenges navigate different treatment approaches and emphasize alternative paths to recovery and healing. (Thomsen 33) Hugh Ryan in “The Postmodern Memoir” (2012) notes that “memoirs are interested in exploring those areas where the metanarrative of truth is at best useless, and at worst, stands in the way of actual comprehension. By highlighting their own

bias and doubt, they are presenting a more honest depiction of life. Furthermore, while they diminish the trust of the reader in the author-as-narrator, they strengthen the reader's trust in the author-as-writer: in a genre rocked by scandal, the writer who admits her own faults seems more reliable than the writer who presents herself as perfect. This is a dangerous line to walk, and the writer who goes too far stands the chance of losing all authority and being disregarded" (Ryan 55). In the book *Pathology and Postmodern: Mental Illness as Discourse and Experience* (1999), Dwight Fee explores "the relationship between mental illness and social constructionism from various fields of study such as sociology, psychology and philosophy. He examines how cultural, economic and historical forces converge in contemporary psychiatry and psychology and how symptoms and subjectivities are constructed and deconstructed in a hyper-reflexive context" (Fee 44). In *Unruly Bodies: Life-Writing by Women with Disabilities* (2007), Susannah B. Mintz explores how female writers with disabilities use their personal narratives to defy societal stereotypes related to disability, gender, and identity. She examines the autobiographical works of eight American writers, highlighting their refusal to conform to inspirational or triumph-over-adversity narratives. Instead, these authors embrace their disabilities as integral aspects of their identities. They candidly discuss issues like shame, medical procedures, work and parenting challenges, sexuality, family dynamics, and the experiences of aging. Mintz's analysis shows that these unconventional stories challenge traditional feminist ideals of independence and self-control while redefining the relationship between embodiment and identity as a whole.

In this dissertation I draw insights from various scholars in the fields of narrative agency, life writing, mental illness, and disability studies. Drawing upon the theories of Katrina Anne Longhurst, Hanna Meretoja, Philip Max Neilsen, Ffion Murphy, Dorthe Kirkegaard Thomsen, Tine Holm, Hugh Ryan, Dwight Fee, and Susannah B. Mintz, I attempt to critically engage with the narratives of selfhood and agency present in the selected Indian texts. By

analyzing how these authors navigate and subvert conventional narratives surrounding disability and mental illness, particularly within the Indian socio-cultural context, I seek to illuminate the complex intersections of identity, trauma, and cultural constructions of illness narratives. The research aims to highlight the diverse strategies employed by the authors to convey their experiences, challenging dominant discourses and offering alternative perspectives on the lived experiences of disability and mental illness. Through this interdisciplinary approach, the research endeavours to deepen our understanding of how storytelling serves as a form of meaning-making and resistance, reshaping notions of identity and agency for individuals living with disabilities and mental health challenges in India.

### **Embodied narratology**

Over the past twenty-five years or so, significant developments in the fields of neuroscience and the philosophy of the mind have been underway. This has impacted our understanding of our relationship of the mind to the body, human consciousness, memory, empathy and intersubjectivity. The developments in neuroscience and the philosophy of the mind have provided a theoretical and empirical foundation for embodied narratology. This interdisciplinary approach recognizes the inseparable connection between the mind and body in the experience and understanding of narratives, acknowledging the importance of sensory, motor, and emotional processes in shaping our engagement with stories. Daniel Punday in his essay, “A Corporeal Narratology?”, in the book, *Narrative Bodies: Towards a Corporeal Narratology* (2003) has expressed his dismay at the failure of the human body to garner attention in narratological studies. To him, a discipline like narratology is overly concerned with the ‘way’ the events, characters and places that make up the story, are presented viz. the discourses at work in a story. The field does not pay adequate attention to the ‘what’ of the



narrative- viz. the event, characters, the narrated of the story. In the Introduction to his book, he insists that the body is the most potent site for narration in narrative theory. He elucidates his views on the narrating body as “a meaningful object, within narrative as it is distinguished from other objects, is defined within a schema of possible bodies” (xv). Punday further notes that, “the body, thus shaped, participates in theories of plot, space, characterization and narration. He considers the body as not merely a “textual object”, but also considers plot structure and linguistic choices of embodied narratives” (54). Marianne Horsdal and Laura Formenti in their essay, “Embodied Narratives: Connecting Stories, Bodies, Cultures and Ecologies” (2014), while acknowledging that, narratives are universal mediums for expressing human experiences, also opine that, the form and structure of the narratives are mediated by certain cultural and social structures and believes that “our stories are embodied” which is a sum total of lived experiences and social interactions (16). This survey of the extant literature on selfhood, agency, disability and mental health studies seems to foreground certain commonalities. Both of these new social movements have tended to overwrite and recover the importance of the corporeal self over the social, ideological and biomedical regulations. Bradley Lewis in his essay “A Mad Fight: Psychiatry and Disability Activism” (2006) outlines that, both disability activism and mental health activism,

face a combined political and epistemological struggle. The very heart of these activisms begins with expressly biomedical assignments of impairment. This comes not in the form of a general pronouncement of inferiority, but in a direct and specific diagnosis and treatment process. Because of this, Mad Pride and disability activist efforts to reduce individualization, medicalization, and ableism require a dual struggle that goes beyond politics-as-usual.... When disability activist and mad pride work together, they can form a formidable coalition. (342)

The reviewed body of work on disability and mental illness, suggest that representations of disability and mental illness have followed different rhythms and patterns of evolution in the

West and in India. These two forms of embodied experiences have a shared challenge rooted in both political and epistemological dimensions. The very heart of these activisms begins with specifically biomedical assignments of impairment. This comes not in the form of a general assertion of inferiority, but in a direct and specific diagnosis and treatment process. Because of this, Mad Pride and disability activist efforts to reduce medicalization, and ableism require a dual struggle that goes beyond politics of the everyday, which entails examining the broader social structures, policies, and practices that shape experiences of oppression and exclusion for people with mental health conditions and disabilities. This includes critiquing systems such as healthcare, education, employment, and the legal system to identify how they contribute to medicalization and ableism. When disability activism and mad pride work together, they can form a formidable coalition. People's attitudes toward these conditions have changed over time, prompting a range of different responses.

A survey of the extant literature on representations of the self and identity in relation to physical disabilities and mental illnesses suggest that certain oppressive institutions (family, workplace, educational institutions, and medical establishments) exacerbate the stigma of living with such conditions. Literary representations of disability and mental illness have, for the most part, reduced the affliction to a 'limitation', 'inertia', 'lack' or a 'deficit'. Some literary works perpetuate stereotypes and stigmas surrounding disability and mental illness. Characters with disabilities or mental health issues are often portrayed as one-dimensional or as villains, reinforcing negative societal biases. Sometimes, authors include disabled or mentally ill characters for diversity's sake without delving into their experiences or challenges. This tokenism can trivialize these conditions and reduce them to mere plot devices. Some literary descriptions focus on eliciting pity or emphasizing the "inspirational" aspect of characters with disabilities or mental illnesses. This can be dehumanizing and fail to represent the complexity of their lives. Writers, at times, tend to oversimplify the experience of disability or mental

illness, reducing complex and multifaceted conditions to overly simplistic narratives. This can lead to a lack of nuance and depth in character development. Literary representations may not reflect the progress made in understanding and treating disabilities and mental illnesses. This can perpetuate outdated notions and hinder societal awareness and acceptance of these conditions. The surveyed scholarship on life-writing, disability, mental health studies and medical humanities have not adequately explored the ways, stories and storytelling are grounded – in situations, in the brain and in the rest of the body- but seems to have focused more on the social, discursive, and institutional situations and contexts which undergird such oppression. There is a need to bring to the fore voices of people living with physical disabilities and mental illnesses by foregrounding, firstly, the materiality of physical disabilities and mental illness and how social variables such as caste, class, gender and citizenship cannot be extricated from experiences of living with disabilities and mental illnesses in India. What is needed to bring together, however, is an intersectional analysis which examine wider determinants of mental health issues such as childhood abuse, dysfunctional families, social relationship, and determinants such as family, gender, caste, nation and the rural-urban divide in the understanding of disability. This dissertation is an attempt to fill these deficits while attempting to recover first person narrative accounts (life-writing and fiction) of people living with physical disabilities and mental illness. One of my concerns shall be to examine how embodied experiences or certain ways of thinking about the body can shape plot, characterization, and setting in life narratives. My purpose then is to show, how the narrating body, while narrating their interior lives, gets enmeshed with the plot, character and the setting. This can also help us in understanding the malleability of autobiographies, memoirs and fiction itself. While addressing questions as to how embodied experiences get enmeshed with narrative structures, I also intend to look at the relationship of these disabled and mentally ill subjects in relation to various alternative modes of cohabitation and self-expression, namely through the act of

writing, the relationship between the caregivers and care-receivers, through embodied storytelling and by advancing certain human right claims by a self-reliant human subject. Their disabilities act as a mediator of social relationships. Next, I examine how experiences of living with physical disabilities and mental illnesses cannot be extricated from other markers of identity such as gender, caste, sexuality and family. Following Alison Kafer and Eunjung Kim's lead, I adopt an intersectional framework for studying disability and mental illness in relation to these markers of identity. Kafer and Kim suggest, "Disability, like age, race, class and sex has a contested history and material effects; as such it merits attention within other analyses of intersectionality" (123). This dissertation shall move from outlining the importance of the lived body in understanding the 'form' of these life writing, to examining how the relationship with caregivers is instrumental to one's understanding of the self, the role that body and memory play in the construction of a narrative, and the various ways in the selected narratives posit a notion of human against the various levels of human right violations. These life narratives are informed by a "cultural schema" framed about disability and mental illness. This cultural schema is a sum total of medical knowledge, cultural perceptions and attitudes, definitions, perceptions, surrounding these conditions, various scientific researches and health discourses. I shall endeavour to show how these memoirs, autobiographies and fiction foreground the undeniable materiality of their disabling condition.

### **Overview of Primary Texts**

➤ *I Have Not Seen Mandu (Swadesh Deepak) ---2021*

Swadesh Deepak's memoir was first published in Hindi as *Maine Mandu Nahi Dekha* in 2003 and it was translated into English as *I Have Not Seen Mandu* by Jerry Pinto in 2021. The book is not merely a journey into the depths of a disturbed mind but also a narrative which charts an

alternative mode of recovering and healing from the effects of depression and trauma. In the memoir, Deepak moves between the past and present to describe a difficult experience and the assuaging effects of the act of narration.

➤ *If I Had to Tell It Again (Gayathri Prabhu) --- 2017*

Gayathri Prabhu in her memoir narrates the experiences of living with clinical depression, a condition which is usually brushed under the carpet. Prabhu describes her relationship to her father who suffers from severe bouts of clinical depression until his demise. She describes the very 'flawed and difficult' relationship with her father. Prabhu succinctly puts it, "That is why, to be silent, I tell myself, would be to collude with the collective denial and discomfort about mental illness. I learnt this about child abuse as well – the most valuable advice is to talk about it, to tell someone, and even though the telling is just a start, it is needed. Otherwise, the shame is muted and the muted stays shameful, slowly snuffing out one's spirit. This is why one writes a memoir. This is why one tells strangers. We carry the invisible, and perhaps the telling can honour it, make it real and seen" (Prabhu 88). Her memoir is an attempt to empower people living with mental health disorders while narrating the lived experiences of clinical depression.

➤ *How to Travel Light: My Memories of Madness and Melancholia (Shreevatsa Nevatia)-- 2017*

Nevatia's memoir describes his experiences of coming to terms with his bipolarity and sexuality, and his addiction to cannabis, caffeine and nicotine. A significant part of his memoir is about the difficulty of narrating the experiences of child sexual abuse which affects his mental health at a later point in his life. For him, writing is a cathartic exercise. He believes that there is an urgent need to create awareness about people living with bipolarity. In an interview, he explains, "One thing I have learnt is that the more you talk about things, the more

you try and give it a guise of a story, the more are people able to participate in your narrative...”  
(Nevatia 12).

- *Beyond the Silence: My Life, My world and Autism (Tito Rajarshi Mukhopadhyay) -----*  
2000

*Beyond the Silence: My Life, The World, and Autism* is an autobiographical novel written by Tito Mukhopadhyay, an autistic person. This memoir is a deeply personal and insightful account of Tito’s life and experiences, particularly as someone living with autism. The book’s narrative technique and style are influenced by Tito’s unique perspective and voice. The book is written in the first-person perspective, offering readers a direct insight into Tito’s thoughts, feelings, and experiences. This narrative style allows Tito to share his personal journey with autism in a highly intimate and authentic manner.

- *Silver Haze (Pankaj Varma) --- 2014*

Pankaj Varma’s autobiographical novel serves as a tribute to his mother who was diagnosed with Alzheimer’s disease and dementia. In his autobiographical novel, the narrator writes down everything that she remembers. Varma highlights the importance of caregiving, memory and interpersonal relationships in his novel.

- *The Other Senses (Preeti Monga) ---2012*

Preeti Monga is an author, activist and the founder of the NGO- “Silver Linings”. Her organization has been working towards the development of visually impaired women in social skills. Her autobiography traces the trials and tribulations she had to face as a person living with optic atrophy in India

➤ *Sun on My Face (Sarmistha Pritam) --- 2014*

Sarmistha Pritam's *Atmakatha* was originally published in Assamese in 2007 and it was translated into English as *Sun on My Face* by Dr. Prafulla Kotoky in 2014. Pritam's autobiography traces the journey of a woman who narrativizes her experiences of living with a mobility impairment. Apart from describing her journey of overcoming the stigma of living with a disabling condition, Pritam underscores the importance of implementing disabled friendly policies in the state.

➤ *fallen, standing: My Life as a schizophrenist (Reshma Valliappan)--- 2014*

Reshma Valliappan's memoir is a collection of emails, diary entries and letters sent by Valliappan to her friend and editor as records of personal experiences. It does not follow a linear pattern. The memoir narrates the lived experiences of schizophrenia and at the same time tries to create awareness about the mental health issues.

➤ *Mrs C. Remembers (Himanjali Sankar) --- 2017*

Himanjali Sankar's novel traces the journey of the three generations of a family which deal with the complex intricacies of family amidst a violent social atmosphere and a formidable health condition of Mrs. Anita Chatterjee- the eponymous character.

➤ *Sepia Leaves (Amandeep Sandhu)--- 2007*

Sandhu's novel tells the story of the young narrator coming to terms with his mother's schizophrenia. It takes the form of a memoir, as the author chooses to dwell on one aspect of his life namely his relationship with his mother. It is told from the perspective of the seven-year-old narrator.

➤ *Em and the Big Hoom (Jerry Pinto) --- 2013*

Jerry Pinto's autobiographical novel vividly explores the relationship of the narrator to his mother who is diagnosed as bipolar. The structure of the novel, which is a conversation between the narrator and his respondents, is interspersed with recollections, anecdotes, diary entries and letters.

➤ *No Looking Back (Shivani Gupta)---* 2014

Shivani Gupta's autobiography offers valuable insights into living with paralysis. It describes Gupta's journey of overcoming a severe accident that leaves her partially paralyzed, highlighting her determination to make a positive impact on the lives of disabled individuals. It explores the various facets of love, grief, and relationships. Shivani's life primarily centres around coping with pain, but rather than dwelling in self-pity, she narrates her experiences with a remarkably optimistic outlook.

➤ *In a Train to Trivandrum (Anirban Mukherjee)-* 2019

Mukherjee's novel revolves around Amitabha Sengupta, a blind and divorced professor who is travelling to Trivandrum to attend a conference. In the course of his journey, he attempts to recover from the memories of the failed relationship with his wife. He encounters various people on his way which helps him recover from the deep abyss.

➤ *Borderline (Shabri Prasad Singh)---* 2017

Borderline has autobiographical references to Singh's own life. It traces the journey of Amrita Srivastava, who is unable to cope with her parents' separation and is diagnosed with borderline personality disorder soon after. Her autobiography traces her battle with her mental health, her addictions and interpersonal relationships.

➤ *Psychlinis (Shama Husain)---* 2018



Husain's novel narrates the story of Sara Ibrahim- the bipolar protagonist, who is the fictional representation of the author herself. She gets her first panic attack after her father's demise. In the novel, we also discover that her father was psychotic. She differentiates between bipolar disorder and mania. Husain believes that these stories of "coming out" need to be told from the perspective of the person who has coped or is still coping with the ailment.

➤ *Blind (Joginder Paul) – 2018*

Joginder Paul's novel was originally published in Urdu as *Nadeed* in 1983 and it was translated into English as *Blind* by Sukrita Paul Kumar and Hina Nandrajog in 2018. It is a narrative which narrates the life stories of the inmates of the home for the blind. Through the various intersecting narratives, the story focuses on the issues of sight and sightlessness, a metaphor on what constitutes sight and looking centering on the interpersonal relationship of the inmates of the home for the blind.

**Rationale for the choice of selected life-writing and fiction**

The texts selected for study encompass a diverse range of themes and narratives. While each work is unique, they do share some common themes and relationships, particularly in the context of personal narratives, disability, mental illness, and autobiographical storytelling. Many of these texts are autobiographical or semi-autobiographical in nature. They are written by individuals who share their personal life experiences, challenges, and journeys. This commonality ties them together in their focus on personal narratives. Several of these texts revolve around the theme of mental health and illness. Authors like Shreevatsa Nevatia, Reshma Valliappan, Shivani Gupta and Sarmistha Pritam, among others, share their experiences with physical disability and mental health issues- such as paralysis, spinal muscular dystrophy, schizophrenia and depression and its seminal influence in shaping their

narratives. The exploration of mental health and disability and its impact on selfhood is a common thread. These works delve into the concept of identity and self-discovery. They reflect on the process of understanding one's self and grappling with personal and societal expectations. This theme of identity exploration is evident in the narratives of authors like Gayathri Prabhu, Shama Husain, and Amandeep Sandhu. Family dynamics and caregiver-care receiver relationships play a significant role in several of these narratives. Authors like Jerry Pinto and Preeti Monga, for instance, explore the complexities of family life and its impact on one's sense of self. These texts often challenge societal stigmas and perceptions associated with various conditions and experiences, including autism, schizophrenia, and mental illness. They contribute to the ongoing discourse on reducing the stigma surrounding these issues. The stories in these texts frequently highlight the resilience and coping mechanisms of the authors in the face of adversity. These narratives can inspire and offer insights into how individuals overcome challenges.

Many of these texts are written in the first person, as they are personal narratives or autobiographical accounts. This narrative style allows the authors to directly share their own experiences and perspectives. The above-mentioned texts often feature a reflective and introspective style, as the authors delve into their own thoughts and emotions. They explore their inner worlds and the impact of their experiences on their psyche. The authors frequently adopt a conversational and accessible tone, making their narratives relatable and engaging for readers. This tone can help readers connect with the author's experiences on a personal level. While the primary focus is on personal storytelling, many of these authors employ literary devices such as metaphors, symbolism, and vivid imagery to enhance the depth and richness of their narratives. Some of these texts use a fragmented or non-linear narrative structure. This style can reflect the author's mental illness or the complexities of their experiences. Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia*, Reshma

Valliappan's *fallen standing: My Life as a Schizophrenist*, Swadesh Deepak's *I Have Not Seen Mandu* and Gayathri Prabhu's *If I Were to Tell It Again* are such example of such self-reflexive texts with a non-linear narrative structure. In most cases, the authors often adopt a candid and honest style, not shying away from sharing their vulnerabilities and struggles. This authenticity is a powerful element of their storytelling. In certain cases, these texts incorporate visual elements, such as photographs or illustrations, to complement the narrative which adds a new dimension to the storytelling such as Preeti Monga's *The Other Senses* and Amandeep Sandhu's *Sepia Leaves*. The lengths and forms of these texts can vary. Some are full-length memoirs, while others may be shorter essays or reflections. This diversity in form allows authors to choose the medium that best suits their narrative. It's important to note that the style of each text is deeply influenced by the author's unique voice, background, and the nature of their personal experiences. Therefore, while these common stylistic elements can be identified, each text maintains its distinctiveness in terms of style and narrative approach.

Despite their stylistic and narrative differences, they share several common themes and motifs. An important concern of all the selected texts is that they demonstrate the power of narrative and storytelling as a means of understanding and processing personal experiences. Authors use storytelling to make sense of their lives and share their perspectives with readers. They explore how cultural norms, expectations, and prejudices can shape an individual's experience and sense of self. These deeply personal and intimate stories chart the journey of transformation and healing, showing how individuals evolve and find a sense of peace, even in the face of significant challenges.

### **Research Objectives**

The objectives of my dissertation include:

- (a) To examine the various ways in which the select narratives attempt to foreground the lived experiences of physical disability and mental illness through the act of writing their life-stories.
- (b) To situate these life narratives within a socio-politico-historical framework by examining how other forms of identity such as gender, sexuality, class and caste intersect with and impact disability and mental health.
- (c) To investigate whether the selected narratives may embody therapeutic elements that transform and give meaning to the individual's lived experience with physical disability or mental illness.
- (d) To evaluate how these narratives depict the ideas of narrative agency, self-identity and care ethics through life-writing and fiction.
- (e) To examine how embodied narration, the body and memory affects the narrative progression and consequently the understanding of selfhood and agency.
- (f) To describe how the select narratives depict a self-reliant narrator who describes the various human right violations in their narratives by 'righting' themselves into the society.
- (g) To examine the various nuances of the relationship between the disabled person and their caregiver which can be instrumental to the understanding of their personhood and in exercising agency and voice through their narrative.

This dissertation shall work at the intersections of the theories of postmodernism, narrative theory, critical disability studies, poststructuralism, psychoanalysis, phenomenology and gender studies. Using these theoretical frameworks, it will draw on the theories of Thomas Couser, Katrina Longhurst, Hanna Meretoja, Ryan Thorneycroft, Roslyn Brooks, Arthur Frank, Rebecca Bitenc, Kay Schaffer, Sidonie Smith, and Alan Parry and others who seem to share a common focus on the intersection of selfhood, agency, disability, and mental illness within

their respective theories and scholarly works. Couser explores how narratives of disability and illness shape a person's sense of selfhood and agency. His work emphasizes the importance of personal storytelling in expressing one's experiences and identity. Roslyn Brooks examines how the therapeutic, healing and cathartic potentials of disability narratives which can empower individuals by giving them a voice and agency. She underscores the significance of telling one's own story to challenge stereotypes and misconceptions about disability. Arthur Frank's work revolves around the concept of "illness narratives," which can also be productively used to studying mental illness and physical disability narratives. He emphasizes the role of narrative in coping with illness and disability, allowing individuals to reclaim their agency and a sense of self. Rebecca Bitenc explores the idea of caregiving, questions of ethics, and mental illness in literature and culture. She discusses how these representations affect selfhood and agency and may contribute to societal change and inclusivity. Using the theories purported by the above scholars and theorists, I attempt to address questions pertaining to the form of these life narratives, identity, selfhood, agency, human rights, body, power, affect and embodiment in relation to gender, class, caste and family. The research analysis shall proceed through a close textual reading and analysis of the primary texts.

### **Structure of the Dissertation**

The dissertation is organized into four chapters preceded by the Introduction, Acknowledgement and Table of Contents and succeeded by the Conclusion.

**Introduction:** The first part of this introduction is focused on exploring the theoretical foundation underpinning this study. The subsequent section will provide a concise overview of the fields of medical and health humanities, literary disability studies, mental illness and literary studies, and the exploration of selfhood and agency in the context of life-writing and fiction. These areas serve as the primary backdrop for this study. The third section of the introduction offers a brief summary and outlines the pertinent contexts for the primary texts examined in this dissertation which is followed by outlining the research objectives, methodology and the rationale for the choice of primary texts.

**Chapter 1: Therapeutic counter-narratives: Reading Gayathri Prabhu's *If I Had to Tell it Again*, Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia* and Swadesh Deepak's *I Have Not Seen Mandu***

In the first chapter of the dissertation, I draw on the theoretical postulations of Roslyn Brooks and Alan Parry to show that the selected life writing can serve as therapeutic counter-narratives to empower, educate, reduce stigma, and promote understanding of physical disability and mental illness, while also advocating for better support systems, and social change. They provide a platform for individuals to share their stories and contribute to a more inclusive and compassionate society. By emphasizing the emotional, psychological, and social dimensions of living with disabilities and mental illnesses, these narratives promote a holistic understanding of these conditions that goes beyond the curative aspects of medicine. I also attempt to show that therapeutic counter-narratives can foster a sense of community and belonging among individuals with disabilities or mental illnesses. It allows them to connect with others who have had similar experiences, providing support and a shared sense of identity.

**Chapter 2: Caregiving and narrative agency in Tito Mukhopadhyay's *Beyond the Silence: My Life, The World and Autism*, Shama Husain's *Psychlinis*, Himanjali Sankar's *Mrs. C Remembers* and Pankaj Varma's *Silver Haze***

In this chapter, I attempt to argue that in the selected texts, the role of the caregiver is central to the disabled and mentally ill protagonist's understanding of their own selves and identity. These narratives explore the tension between needing assistance and wanting to lead an independent life. Drawing on the theories of Rebecca Bitenc, Hanna Meretoja and others, I submit that the select literary care narratives raise ethical questions related to caregiving, such as the decision-making process regarding treatment, medication, or end-of-life care. These dilemmas can be thought-provoking and challenge readers to consider the moral aspects of caregiving. Caregiving experiences are not one-sided. Caregivers also undergo personal growth and transformation. Their collaborative storytelling is a strategy through which the narrative agency is exercised. The role of caregivers has also been studied for their capacity to be "relating narratives" that take on the ethical task of chronicling and bearing witness to aspects and events that are inaccessible to the person living with the condition.

**Chapter 3: Embodiment, subjectivity and self-identity in Jerry Pinto's *Em and the Big Hoom*, Shabri Prasad Singh's *Borderline*, Amandeep Sandhu's *Sepia Leaves*, Anirban Mukherjee's *In a Train to Trivandrum* and Joginder Paul's *Blind***

In this chapter, I attempt to argue that the selected texts by Jerry Pinto, Shabri Prasad Singh, Amandeep Sandhu, Joginder Paul, and Anirban Mukherjee offer innovative modes of

embodied storytelling. Taking my cue from Susannah B. Mintz, Rebecca Bitenc, Pia Kontos, James B. Nelson and others, I argue that the select narratives explore how individuals living with physical disabilities or mental illnesses employ inventive strategies to narrativize the embodied aspects of their condition despite the physical, psychological, and narrative challenges posed by their conditions. In the proposed texts, I also attempt to emphasize the significance of embodied selfhood and embodied communication as a discursive space where cultural and political discourses intersect, particularly for individuals living with disabilities or mental illnesses.

**Chapter 4: The self-reliant human subject: Narrativizing human-rights in Reshma Valliappan's *fallen standing: My Life as a Schizophrenist*, Preeti Monga's *The Other Senses*, Shivani Gupta's *No Looking Back* and Sarmistha Pritam's *Sun on My Face*.**

The primary thrust of this chapter is to examine the intersections between human rights and literature particularly in the selected life writings that focus on physical disability and mental illness. Both literature and human-rights focus on narrativizing stories of distress and trauma. Drawing on the scholarship of Anthony Langlois, Elizabeth Anker, Pramod K. Nayar, Christopher Krentz and others, I maintain that the selected life writing texts encompass various modes of writing or 'righting' their identities by depicting various coping strategies and ways of resilience in the face of debasement of their human-rights and selfhood. They are signposts for promoting human rights and social change by encompassing diverse modes of storytelling used by the narrators who have experienced human rights violations, whether through autobiographies, memoirs, or email conversations. Such human-rights narratives are considered valuable not only for their factual accounts but also for the various registers of truth they represent, including psychological, experiential, historical, cultural, and communal truths.



The act of personal narrating is portrayed as a balancing act between traumatic memories of the past and hopes for an enabling future.

## **Conclusion**

The conclusion recapitulates the ideas explored in the dissertation. In this dissertation I tried to examine Indian life-writing and fiction on physical disability and mental illness in the early twenty-first century. In the preceding chapters I tried to show that these narratives serve as therapeutic counter-narratives, offering guidance for mental health, informed decision-making, and self-advocacy. They empower writers to share their stories and provide valuable insights for researchers and clinicians. These texts also present an alternative view of selfhood, complex relationships with the body, and act as human rights advocacy narratives for inclusivity and social change. The first chapter explored how literary therapeutic counter-narratives help individuals cope with distress, heal from trauma, and offer alternative perspectives on disability and mental illness. The second chapter focused on caregiving narratives, highlighting the essential role of caregivers and their evolving relationships with care recipients. The third chapter delved into the role of the embodiment in remembering and narrating experiences of disability. The fourth chapter placed these narratives within a human rights framework, highlighting violations of disabled and mentally ill individuals' rights. In this chapter, I argued how the writers 'right' their identities by advocating various alternative coping strategies in the face of debasement of their human-rights. I then discuss some of the limitations of the current research and humbly attempt to suggest new avenues of enquiry for researchers working at the crossroads of literature, disability, mental illness studies, health humanities and narrative medicine

## CHAPTER ONE

**Therapeutic counter-narratives: Reading Gayathri Prabhu's *If I Had to Tell it Again*,  
Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia*  
and Swadesh Deepak's *I Have Not Seen Mandu***

**The Pain Reliever**BY CARRIE OLIVIA ADAMS<sup>11</sup>

Silence is the sound the knife makes  
slitting the skin.

Can you identify my weakness, a pricking sensation  
and numbness in one limb?

Can you hold this tongue?  
Tell me, what is the function of meticulous courage.

You are the most yourself  
when you are in the motion.

One can be quick and too quick.  
I have a stomach too.  
It gets hungry.

If I be of necessity  
opportunity,  
if there be the slightest chance of success,  
why have a mind, if?

Does that scream in the night across the alley  
beg an answer? Are we crowning  
into the sludge of an injury and its repair?

An elephant is larger and stronger than a horse;  
but it is not preferred as a beast of burden.

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<sup>11</sup> Carrie Olivia Adams lives in Chicago, where she works in publishing and serves as the poetry editor for *Black Ocean*. She is the author of *Operating Theater* (Noctuary Press, 2015), *Forty-One Jane Doe's* (Ahsahta, 2013), and *Intervening Absence* (Ahsahta, 2009), as well as the chapbooks *Grapple* (above/ground press, 2017), *Overture in the Key of F* (above/ground press, 2013), and *A Useless Window* (Black Ocean, 2006). (Source: poetry foundation)

Strength is a wee umbrella in the storm.  
This the friction sound heard  
in inspiration, expiration, or both.

For convenience of description,  
blood is bright red and frothy.

Have you earned the privilege  
of making mistakes?

There really is no sex in science.

The nomenclature lifts  
delicate subjects up from the plane  
in which language places them.

Man has more strength,  
woman, more endurance.

The hands and the instruments  
are the chief sources of danger.

This fever.  
There is no subject on which so much has been written  
and so little known.

### **Revenant**

**BY MEENA ALEXANDER<sup>12</sup>**

This disease has come back  
With frills and furbelows.

You must give your whole life to poetry  
Only a few survive if that—

Poems I mean, paper crumpled  
Shades of another water—

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<sup>12</sup> Meena Alexander was a poet, novelist, and essayist born in Allahabad, India, and raised in Kerala and Sudan. She held a Ph.D. from Nottingham University and was celebrated for her poetry, exploring themes of migration, trauma, and reconciliation. Her works include "Illiterate Heart," winner of the PEN Open Book Award, and "Atmospheric Embroidery." Alexander's fluency in multiple languages informed her poetry, allowing her to embrace linguistic ambiguity. She authored memoirs, novels, and critical studies and was known for her contributions to postcolonial literature. She received numerous grants and awards during her career, teaching at various universities, including Columbia University and the University of Hyderabad. (Source: poetry foundation)

Far springs are what you long for,  
Listening for the slow drip of chemicals

Through a hole in your chest.

If you were torn from me  
I could not bear what the earth had to offer.

To be well again, what might that mean?  
The flowering plum sprung from late snow,

Ratcheting trill in the blackberry bush  
Blood streaks, pluck and throb of mercy.

Both “The Pain Reliever” by Carrie Olivia Adams and “Revenant” by Meena Alexander can be read as therapeutic narratives that explore the theme of illness and healing, although they approach the subject from different perspectives and use distinct imageries. Both poems reflect on the experience of illness and the challenges it presents. In “The Pain Reliever,” the speaker contemplates pain, weakness, and the human condition. In “Revenant,” the reference to a disease returning with “frills and furbelows”, suggests a complex, possibly recurring, illness. In “The Pain Reliever,” the speaker grapples with vulnerability and the human condition, which can be therapeutic by providing a space for acknowledging and expressing difficult emotions. In “Revenant,” the desire for healing and the longing for wellness evoke a sense of emotional struggle, which can also be therapeutic for readers dealing with illness. Both the poems use metaphorical and symbolic imagery to convey their themes. In “The Pain Reliever,” there is imagery related to knives, strength, and vulnerability. In “Revenant,” the reference to “paper crumpled” and “shades of another water” employs metaphor to symbolize the fragility and transformation of life in the face of illness. These metaphors allow readers to engage with the subject matter on a deeper level and provide a therapeutic lens through which to view the experience of illness. Both Adams and Alexander touch on the idea of acceptance and the

search for healing. Both poems create spaces for emotional exploration, reflection, by conveying the complex and often challenging nature of illness and the human condition. These poems provide a means for individuals dealing with illness to find solace and understanding, making them valuable tools for therapeutic exploration and healing.

The primary aim of this chapter is to show that the selected life writing can serve as therapeutic counter-narratives to empower, educate, reduce stigma, and promote understanding of physical disability and mental illness, while also advocating for better support systems and social change. They provide a platform for individuals to share their stories and contribute to a more inclusive and compassionate society. By emphasizing the emotional, psychological, and social dimensions of living with disabilities and mental illnesses, these narratives promote a holistic understanding of these conditions that goes beyond the curative dimensions of medicine. I also attempt to show that therapeutic counter-narratives can foster a sense of community and belonging among individuals with disabilities or mental illnesses. It allows them to connect with others who have had similar experiences, providing support and a shared sense of identity. Therefore, the select narratives not only attempt to assuage distress or foster empathy but also help in expunging the traces of the trauma that constitutes the story in the first place. Wright and Chung published a review of the literature in which they claimed that writing therapy had been “restimulated by the development of narrative approaches” (278). Pennebaker argues that “catharsis or the venting of emotions” without “cognitive processing” has little therapeutic value and people need to “build a coherent narrative that explains some past experience” in order to benefit from writing” (Pennebaker, 10-11). Even in the domains of literary disability studies and mental illness and literary scholarship or mad studies, life writing could have “therapeutic benefits of, for example striking physical health and behaviour change” (Esterling et al. 84). Pennebaker and Seagal argue in the *Journal of Clinical Psychology* that life-writing process-

allows one to organize and remember events in a coherent fashion while integrating thoughts and feelings... This gives individuals a sense of predictability and control over their lives. Once an experience has structure and meaning, it would follow that the emotional effects of that experience are more manageable. (1243)

The texts I propose to study in this chapter include Gayathri Prabhu's *If I Had to Tell It Again* (2017), Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia* (2017) and Swadesh Deepak's *I Have Not Seen Mandu* (2021). I begin by ascertaining that the aforementioned life-writing construct a positive recovery narrative through their story-telling which may have a positive therapeutic effect creating narrative agency, a sense of connectedness and creativity. Emphasizing that human beings view their lives as stories, In *Making Selves*, Paul Eakin suggests that, "narrative is not merely a literary form but a mode of phenomenological and cognitive self-experience, while self- the self of autobiographical discourse- does not necessarily precede its constitution in narrative." (100). In this chapter, I examine four life-writing as examples of therapeutic narratives- which potentially have a healing function and may supplement a bio-medical understanding of mental illness which locates the cause of the medical condition in the body of the person. As disability and mental illness narratives centre on the body as the focal point of lived experience and the search for meaning within those experiences, I submit that mental illness narratives serve as a cathartic exercise by providing a comprehensive account of the various material realities that are associated with the condition. Therapeutic writing has a healing function that gives meaning to disability and mental illness. Roslyn Brooks in "Therapeutic Narrative: Illness writing and the quest for healing" identifies perversity, empowerment and transformation as the key elements that serve therapeutic functions (Brooks 12). The very act of telling one's story has a healing purpose by working as a salve to a trauma that might have triggered the telling of the story. It does not merely challenge the all-pervasive stigma and shame but creates a sense of community

with people who live with such conditions. Disability and mental illness narratives are generally counternarratives which challenge the parochial views of an ableist or sanist society that sees disability and mental illness as a condition that needs to be corrected. Such narratives also have the potential of creating an altogether different kind of narrative in which the person who has been divested of the status of human takes on the imperative of narrativizing their lived experiences.

The narrative approach to medicine attaches importance on the idea of telling one's life story as a healing exercise which has therapeutic potentials. Although the narrative approach to medicine places singular emphasis on illness narratives, the elements of narrative therapy—the search for one's life story can be productively employed to study disability and mental illness life narratives and fiction as well. Roslyn Brooks identifies “Alida Gersie's use of narrative in her work on ‘therapeutic storymaking’”. Here she employs stories, myths and patients' stories and new fiction which aids her in group therapy. Gersie's work has been significant in highlighting the power of storytelling or narrativizing one's life story to bring about change across a variety of psychosocial disorders and ailments” (Gersie in Brooks 54). Along similar lines, Brooks refers to “Ellen Siegelman, Barbara and Richard Almond and James Phillips who have used various imageries and metaphors to highlight the power of the written word. They seem to look at narratives as narratives of psychosocial development and conflict resolution. James Phillips opines that narrative is the core of human identity, that the terms narrative identity and personal identity become almost interchangeable” (Siegelman, Almond et.al quoted in Brooks 44). In a similar vein, Alan Parry, in “A Universe of Stories,” discusses how the narrative dimension plays a central role in comprehending an individual's life experiences. Parry asserts that narrative therapy is premised on the idea that we employ storytelling to interpret and give meaning to our experiences. He emphasizes that our lives and identities are intricately woven into the stories we construct. The core concept of narrative

therapy is that individuals have the capacity to transform restrictive and harmful beliefs they hold about themselves, and in doing so, they can unlock new possibilities for their lives by reimagining and retelling their personal narratives (43). Therapeutic narratives are postmodernist in the sense that such stories which help in healing, do not privilege certain fixed truths, knowledge and identity and is constantly in the process of becoming which is moulded by socio-cultural and historical factors. There is no overarching narrative voice in these stories and the identity established in these narratives provides liberating opportunities, opportunities for self-fashioning and self-remaking. Mary Karr writes that, “In terms of cathartic effect, memoir is like therapy, the difference being that in therapy, you pay them,” (22). Research in the fields of experimental psychology and biomedicine has demonstrated that individuals, who are not professional writers or artists, can experience health benefits by engaging in expressive writing about their life experiences. These benefits extend to people who do not necessarily aim to create aesthetically pleasing or artistic works in their writing. (Valtonen 4). Literary critics and philosophers observe that narratives are psychologically essential for how human beings come to an understanding of their selves. According to bioethicist Howard Brody, “the primary human mechanism for attaching meaning to particular experiences is to tell stories about them” (13). Fredric Jameson calls narrative the “central function or instance of the human mind” (Jameson quoted in Abbott 1). Sociologist Arthur Frank opines that stories are the self’s medium of being, it is “a rage for order” (Frank).

### **Narrative therapy and catharsis in Gayathri Prabhu’s *If I Had to Tell It Again*:**

#### **Exploring healing through personal storytelling.**

Gayathri Prabhu is an Indian writer whose works thematize family dynamics, storytelling, and the complexities of mental health, amongst others. Her novels are characterized by their poetic



and expressive style. Her memoir, *If I Had To Tell It Again* (2017), is a deeply personal account which narrates her challenging relationship with her depressive father. The narrator of Gayathri Prabhu's memoir questions what it means to be living with clinical depression in a society where it is perceived as an anomaly. The memoir provides insight into the intricate dynamics within Prabhu's family, particularly the relationship between the author and her father. It delves into the complexities of love, compassion, and understanding in the context of a family dealing with a member's mental health issues. As the author recounts her experiences, she undergoes a process of self-discovery and growth. Her journey includes coming to terms with her father's condition, her own emotions, and her evolving understanding of mental health. The title itself suggests the importance of storytelling in the book. Prabhu's narrative style is lyrical and introspective. She weaves a compelling story that engages readers on both emotional and intellectual levels, highlighting the power of storytelling as a means of catharsis and self-expression. I seek to explore two questions in this section, how does a personal story on trauma, illness and memory become a potential source of healing, and what are the key elements of a therapeutic narrative. As stated earlier, therapeutic narratives take a postmodernist approach by challenging the basis for medical understanding. Instead, they aim to introduce an alternative perspective on recovery and healing. Prabhu's memoir foregrounds the subjectivity of illness in two ways: the protagonist who experiences mental illness is the central subject and whose illness has a personal and emotive meaning. Story and discourse are the essential components of any narrative. While the former consists of the story being told, the latter is the telling of the story. Postmodern narratives on depression have unsettled or problematized certain dominant ways of understanding mental health disorders. In the domain of biomedicine, there has been a gradual shift from an overarching bio positivist model of health and illness to a more holistic model which takes into account various patient narratives with a focus on the rights of patients, involvement in treatment and their autonomy. However, there is still a deficit in addressing the

socio-cultural stressors contributing to mental illness. While discussing the narrative approach to mental health, John Launer observes that, “psychiatry lies in an uncomfortable no man’s land between conventional medical science and the search for meaning” (117). In stories of disability and mental illness, like postmodern narratives, the narrative is always in a state of becoming in its quest for meaning. Prabhu’s non-linear narrative structure, digressions and change of narrative voices in the memoir suggest the difficulties of narrating a mental illness story. This act of telling one’s afflicted life story may generate empathy on the reader’s part. According to Anderst, these digressions generate empathy in bringing the reader closer to the narrative and they seem to be closer to the narrating-I than the experiencing-I, as the author constantly shifts between personal experience and social and cultural analysis of living with a medical condition. Roslyn Brooks writes that, “powerful illness narratives are often characterized by perversity, overturning the assumptions of dominant cultural discourses – including those that place authority with the medical practitioner and demand acquiescence from the patient. The most powerful therapeutic narratives transform the story of illness into a new story” (12). In the concluding section of the memoir, Prabhu succinctly writes about the problems of writing a memoir in India which cannot extricate questions of family, duty, responsibility:

And I know why there are such few memoirs being written in this country about the sort of suffering that only families can inflict and endure. The rhetoric of duty, sacrifice and family honour turns ceaselessly like a giant oil press. (124-25)

Here Prabhu seems to highlight the transformative potential of storytelling in the context of mental illness. Prabhu suggests that through the act of narrating one’s experiences, individuals can reshape their understanding of illness, moving beyond mere suffering to find new meaning and perspective. The concluding section of the memoir reflects on the challenges of writing about personal suffering within the cultural context of India, where familial obligations and

societal expectations weigh heavily on individuals. Prabhu acknowledges the difficulty of extricating personal narratives from the complexities of family dynamics, duty, and societal norms. The metaphor of the “giant oil press” evokes the relentless pressure and constraints imposed by traditional values and familial responsibilities. Alan Parry in ‘A Universe of Stories’ (1991) argues that “narrative therapy begins from the notion that we use stories to make sense of the meaning of our experience- our lives and our identities reside in the stories we narrate. The crux of narrative therapy or therapeutic storytelling is that a person can change constricting and damaging beliefs they hold about themselves, and open new possibilities of life, retelling the story” (43). Parry argues that ‘the goal of therapy, understood as “restorying,” would be to facilitate a process in which a person finds her own voice to tell a story of her description of her experiences (44). This involves empowerment, validation of the person’s experience and selfhood, ‘she takes charge of her own story’ and ‘she experiences herself in effective charge of her own life’ (Parry 44). Prabhu’s strained relationship with her father is the fulcrum of the narrative. In her essay “Narrative Humility” (2008), Sayantani DasGupta observes that the stories shared by our patients are not static, comprehensible objects that we can fully grasp or control. Instead, they are dynamic narratives that we can interact with, always being receptive to their potential for ambiguity and contradiction. Simultaneously, we must engage in ongoing self-evaluation and self-critique, considering matters such as our role in the story, our expectations of it, and our personal connections to it. These connections may be due to how the story resonates with us or reminds us of personal stories, which can be either attractive or repelling (981). Although the primary aim of Prabhu’s memoir is not garnering empathy but to show how the act of storytelling can have a cathartic effect on the narrator since they provide a form of emotional release of restrained trauma. In her memoir, Gayathri Prabhu recognizes that one cannot narrativize the lived experience of depression in a coherent manner. She writes:

The story of depression is hard to tell, always in fragments, hard to cast in words, hard to tell when it seeped out of him, into and through me. Like that legacy of storytelling...He was always telling stories, embellishing every narrative, introducing dramatic interludes, enacting scenes, inviting laughter and comments, as if on a stage, as if on a spotlight. My father, the showman, revelled in repetition, in amplifying details to the elastic limits of credibility. Some of these stories I heard more times than I can count. No two tellings were alike, and yet every telling felt like the most plausible, most immediate, such was his gift. (Prabhu 9)

Prabhu stresses that depression defies easy articulation, much like her father's penchant for dynamic and innovative storytelling. Despite the inherent difficulties, she acknowledges her father's storytelling abilities emphasizing on the persuasive nature of his narratives, even if they vary in each retelling. Alan Parry emphasizes the playful, imaginative, 'poetic' aspect of narrative making. He emphasizes on the use of language, metaphor through which the narrator seeks to purport their idea. He also describes the inventiveness and playfulness of such narratives through which narratives attempt to subvert monolithic knowledge of a health condition (Parry 39). Parry suggests a place for the perverse and transgressive- 'the received text or life-story in its constraining role' is challenged and undermined by 'alternate stories, unexpected interpretations...paradoxical stories' (52). Parry's idea of narratives challenging and undermining the "received text" or the dominant, constraining life-story is relevant to Prabhu's memoir- *If I Had to Tell It Again* which explores the complexities of caregiving, love, and personal identity in the face of a debilitating health condition. Prabhu's narrative subverts the conventional narratives of illness and caregiving by providing alternative perspectives and experiences that challenge stereotypical or monolithic understandings of such situations. Prabhu's memoir is not just a straightforward account of her experiences but is infused with creativity and imagination. She uses language and storytelling techniques to convey the emotional and psychological complexities of her journey. Her narrative style is not merely informative but also emotive and imaginative, contributing to a more profound understanding

of the subject matter. Parry's emphasis on the use of metaphor and language aligns with how Prabhu crafts her narrative. She employs metaphors, symbols, and figurative language to convey the emotional and psychological impact of her father's condition. Parry suggests that narratives can challenge conventional wisdom through paradoxical stories. Prabhu's memoir presents paradoxical elements, such as the simultaneous burden and blessing of caregiving, the dual role of a daughter as both caregiver and individual, and the way her father's condition both constrains and liberates her. These paradoxes challenge simplistic or one-dimensional narratives of illness and caregiving. Alan Parry's view on the playful, imaginative, and subversive aspects of narrative making is relevant to a reading of Gayathri Prabhu's *If I Had to Tell It Again*. Prabhu's memoir embraces these qualities, providing a nuanced, emotionally resonant exploration of caregiving and the impact of a health condition on personal identity and family dynamics. Prabhu's memoir narrativizes the aftermath of her father's death and the various ways in which she tries to cope with the trauma and the ensuing depression. Addressing the dual challenges of depression, addiction, and their psychological consequences, Prabhu's memoir is a humble attempt to rebuild her connection with her deceased father. She believes it is her responsibility to narrate her deceased father's story. This act of re-storying her strained relationship with her father in the form of a narrative is a cathartic experience for her. Katherine Borland in "Co-narration, Intersubjectivity, and the Listener in Family Story-Telling" (2017) observes that the listener takes up, reshapes and dialogizes as one moves from receptive audience to that of a responsive performer (12). Prabhu decides to narrativize the story of her father's life as a way of healing her relationship with her father. In her memoir, Prabhu engages in the act of reconstructing her life story, particularly her relationship with her father, which serves as a means of empowerment and self-discovery. This act of storytelling allows her to validate her own experiences and take charge of her narrative. Prabhu's memoir is a testament to her own agency as the narrator of her life story. By telling her own story and recounting her

experiences, she takes control of the narrative. This process can be empowering because it allows her to shape and understand her life in her own terms. She confronts the “damages and faults” in her relationship with her father and acknowledges them, which is a crucial step in the healing process. Prabhu’s memoir reflects her journey to mend and heal the complex father-daughter relationship that forms a central theme of the narrative. By recounting her experiences and emotions, she seeks to come to terms with the past and find a sense of closure and reconciliation. Thomas Couser’s idea of counter-narratives performing a healing function aligns with Prabhu’s approach in her memoir. Her memoir can be seen as a counter-narrative to the dominant or traditional narratives that account for the lived experiences of clinical depression. By offering her perspective and personal story, she engages in a healing process that challenges and reshapes the narrative. Writing does not ‘cure’ illness, but part of the suffering of illness is caused by the prejudicial discourse that surrounds it- the myths, the ignorance, the stigmatization: ‘It is this gratuitous collateral damage... that counter-discourse in the form of illness narratives can address and perhaps alleviate’ (Couser 289). The therapeutic functions that Couser identifies in illness writing include validating the experience of illness and discovering meaning in the disruption it makes in the life narrative. One of the disruptions of illness is separation from the social network: illness narratives may serve to reconnect the person to the family or wider community. Illness writing can seek or affirm belonging: ...foregrounding of embodiment as a basic condition of our humanity: illness narratives can serve as a ‘reality check... remind[ing] us of the vulnerabilities of embodiment’ (Couser 295). Couser further notes that illness [and disability narratives] demystify the taboo subjects of embodiment and disease and in this way contest stigmatization and alienation of sick people. They can ‘reclaim bodies from medical colonization’ (Couser 295), contesting the depersonalizing aspects of biomedical technologies and setting up a counter to the master discourse of medicine. The narratives of disability and illness may attempt to resist

disempowering master discourses and assert personal agency. Apart from exercising narrative agency, the narrator seems to invoke a particular community of sufferers who have had to endure a similar condition. Thus, Prabhu's narrator essentially places itself within the context of a larger community. This invokes the idea of Alan Parry who held the view that:

Narrative allows connection, the therapeutic function of placing our own story in the wider context of community. We can transcend our limited individual view through imagination and curiosity, sharing other people's experience through hearing their stories, and 'connect ourselves to... those larger epic stories of our communities, our cultures, our humanity'. (Parry 53)

Although Parry talks about the inventive and creative potentials of language to convey one's story, he also describes the use of various allusions, metaphors and images and most importantly, 'a certain playfulness' which problematizes certain master narratives which assume to have understood and comprehended the self. In a way, texts such as Prabhu's have a transgressive and a subversive potential of positing an alternative story. As the story unfolds, the narrator slowly uncovers the potential factors that could have contributed to her father's lifelong struggle with depression, starting from his childhood. Significant changes and developments in his moods and temperaments occur after his marriage, which is arranged with the consultation of the adults in the family. The memoir opens with the narrator receiving the news of her father's death after which she feels that something has been released inside her (Prabhu 1). The word "released" implies a kind of emotional liberation or surfacing of intense feelings that were previously held within. This could indicate a flood of emotions, memories, or reflections that are triggered by the news of her father's passing. The release might encompass a range of complex and deep-seated emotions associated with the relationship with her father and the subsequent journey of grappling with depression. This release is a transformative moment which she tries to unfold through her memoir. Prabhu endeavours to "restore" both her father's narrative and her own journey of living through the depths of

depression. Initially, the narrator explains that her father had long entertained thoughts of death but exhibited a “plaintive” desire to continue living after receiving a diagnosis of liver dysfunction from doctors. However, unable to cope with the stresses of life, he succumbed to substance abuse and alcoholism. The burden of narrating the story of a depressive parent falls on her, and she stumbles upon her father’s diary after his passing. This diary contains glimpses of his life before the onset of depression, where her father appears to have actively “courted life” (Prabhu 3). The narrator’s father has the habit of censoring information even as he revealed certain bits of information about his life. Prabhu’s memoir does not directly narrate a story of recovery or cure. In his memoir on depression- *Darkness Visible- A Memoir of Madness* (1989), William Styron provides an insight into the workings of one’s subjective world. He opines that language is inadequate to narrate the lived experiences of depression. According to Styron, the world has slithered innocuously through the language like a slug, leaving little trace of its intrinsic malevolence and preventing, by its very insipidity, a general awareness of the horrible intensity of the disease when out of control (37). One of the most damaging qualities of depression, according to Styron, is that the melancholic condition defies adequate description through language and much of the experience is lost in translation failing to take stock of the actual experiences (38). Styron’s notion that much of the experience is lost in translation and that depression defies adequate description resonates with the difficulty Prabhu faces in narrating her father’s story and her own journey through the depths of depression. Both Styron and Prabhu seem to share the perspective that the language may not fully capture the depth and intensity of the emotional and psychological turmoil associated with depression. The narrator of Prabhu’s memoir acknowledges that there was something amiss in her father’s mind. She writes,

Surely there must have been demons in his head. He had twenty-six years before I was born, years that must have steeped in humiliations, disappointments, heartbreak. Hadn’t



he been raw and sensitive? Hadn't he been naïve and trusting? Always the most entertaining in a gathering, hadn't his loneliness over the unsharable, his agony over lost dreams been crushing? (10)

Prabhu notes that pain endlessly spawns more pain and that pain can never heal. However, the narrator is unsure of where to begin telling her father's story-she cannot seem to decide whether to begin with her father's younger days, older days or by describing his life as a series of triumphs. She narrates her father's life from the first two perspectives and then she realizes it soon after that it is futile and starts afresh, thereby underscoring the difficulties of narrating a linear narrative of one's experience with depression. Further, Prabhu notes that her father "the showman" never narrates the same story twice (Prabhu 12). There is always a contradiction between his stories which constituted the tussle between the sober and the manic sides of her father. Her memories of her father predominate most of her childhood and her mother pales into insignificance. Her narrative is infused with pain and regret as she recounts her relationship with her father, who refuses to acknowledge his depression and battles with alcoholism. Although she realizes that her father was spiralling into addiction, but she feels that she was unable to do anything. Prabhu's memoir brings in divergent genres into play in her narrative. An entire section of her narrative, "Leap" examines a dialogue between her sober and manic selves, structured in the form of a play. As his most doting child, Prabhu had to live up to the father's expectations. She unveils the imperfections within what appeared to be an ideal relationship, exposing the hidden flaws. These gaps, or as she refers to them, "holes" within her father's story, seem to captivate her, leading her fill these voids. It is at her father's funeral that people urge her to write her father's story. For the narrator, her father was "the consummate weaver, the finest storyteller" and she is "gatherer of the gaps, the unspoken" (Prabhu 14). Prabhu characterizes her narrative as imperfect, highlighting the presence of gaps and lacunas, akin to a sieve. Through this, she challenges the conventional notion of presenting a chronological, linear, and all-encompassing narrative of their lives. She writes:

There are holes in this story and it looks like a sieve. Not because I forget, but because the holes fascinate me more than the woven strands around them. He was the consummate weaver, the finest storyteller I knew. And I was the gatherer of gaps, the unspoken. (Prabhu 23)

Although Prabhu's memoir does not compromise or break the "autobiographical pact"<sup>13</sup> envisioned by Lejeune, she seems to expose the limitations of such a pact by presenting to her reader a discontinuous and non-linear narrative. In one of her interviews, Prabhu underscores the importance of telling stories of depression:

That is why, to be silent, I tell myself, would be to collude with the collective denial and discomfort about mental illness. I learnt this about child abuse as well- the most valuable advice is to talk about it, to tell someone, and even though the telling is just a start, it is needed. Otherwise, the shame is muted and the muted stays shameful, slowly snuffing out one's spirit. This is why one writes a memoir. This is why one tells strangers. We carry the invisible, and perhaps the telling can honour it, make it real and seen. (Prabhu 35)

By outlining the need to tell her story, Prabhu attempts to make the collective denial of depression real and seen. In Prabhu's memoir, exercising agency is one of the ways of appraising one's self through an emotional engagement in attempting to narrate a difficult story. Prabhu stresses that her father never accepted his "vortex of darkness" (Prabhu 128), that was a product of his circumstances and his inability to cope. The narrator is not able to "purge off" (Prabhu 130) many of her father's tendencies that she had inherited from him, which included his depression. She constantly engages in an imaginary conversation with her deceased father for inspiration. The narrator recollects that her father kept a record of his everyday life, which registers his inability to cope with the vagaries of everyday life. Her father- a man who died in 2014 used a diary that belonged to 2001, wrote about the past. While going through her father's

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<sup>13</sup> The autobiographical pact, introduced by Philippe Lejeune, is an unspoken agreement between autobiographical authors and their readers. It entails the author's commitment to present their life story truthfully, and the reader's expectation that the account is authentic. This concept underlines the unique nature of autobiographical writing and the mutual trust between author and reader in conveying life experiences honestly.

diary entries which contains poems, quotes, words of wisdom, with certain pages completely devoid of any writings and certain entries carefully sorted and selected, the narrator feels she is eavesdropping into his private life. In her dialogue with her deceased father, she also hints at an encounter with her “other,” which encompasses her alternating states of sobriety and mania. A section titled “Leap,” which takes the form of a one-act play within the memoir, introduces three characters: W (a woman in her forties), M (a man in his sixties), and S (representing various possibilities such as a shadow, a woman, the narrator’s or W’s alter ego, a voice in the woman’s head, the illness, or the divide that existed between the father and the daughter. The use of this literary device within the memoir can be interpreted as an exploration of “alterity.”<sup>14</sup> She writes:

W: Do we write as we remember, or do we remember as we write?

S: We don’t remember at all. We bead together words, call it a memory. Writers are such cheats. Ask your father.

W: I hated it when people spoke my life- how can I do the same to him? But you can write about me, and I will tell you about him...

S: I don’t recommend it. Your life is small, and there is the sea of unknown around it, full of perils. Anything you say can spear someone’s heart, be refuted, denied, damned. You think you are telling the truth, but the truth is a parody. You can never get it right, and I have learnt to forge ahead, to get it wrong. Wrong, but in the right tenor, like crossing between lives. Believe me, being dead is not complicated as people make it out to be.

(Prabhu 47)

Prabhu recognizes that the one-act play deviates from the typical characteristics of the memoir challenging the conventional process of constructing memories and highlights the complexities

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<sup>14</sup> “Alterity” is a philosophical and anthropological concept that refers to the state of being other or different from oneself. It relates to the idea of otherness or the recognition of the existence of the other, often in contrast to the self or one’s own group. It is used to explore the differences and distinctions between individuals, cultures, or entities. The term “alterity” has its origins in Latin. It comes from the Latin word “alter,” which means “other” or “another.” The concept has been widely discussed in fields like philosophy, anthropology, and sociology to understand the nature of relationships, identity, and the perception of differences between individuals or groups. The term is closely associated with philosophers like Emmanuel Levinas and Jacques Derrida, who explored the philosophical implications of alterity.

of truth and storytelling. It is a narrative device she uses to dramatize her relationship with her deceased father, and therefore she feels the need for a stage where this relationship can be enacted. She expresses her desire to disrupt any voyeuristic or sensationalized consumption of her life and representing her story as a series of tragic events. Instead, she invites the reader to actively engage and participate in her narrative. The narrator says that, “We don’t remember at all. We bead words, call it a memory. Writers are such cheats, [...] You can never get it right, and I have learnt to forge ahead, to get it wrong, but in the right tenor, like crossing between the lives (Prabhu 46-47). In these lines, Prabhu suggests that memory is not a perfect or accurate representation of the past. She uses the metaphor of “beading words” and calls it a memory. He also implies that writers, in their attempts to capture and convey memories, are somewhat deceptive or “cheats” because they can never fully recreate the past in its entirety. Despite this, she acknowledges the value of forging ahead and getting things wrong in the right way, suggesting that the essence or emotional tone of a memory is what matters, rather than strict accuracy, and that this can help bridge the gap between different lives or experiences. This play brings Prabhu’s awareness of the performance of memory to the forefront. The play is fittingly titled “Leap” and it encapsulates the appropriate tenor of telling the story rather than what is being told. Narrating one’s self does not necessarily follow a logical succession of events but it can only be addressed by looking into the gaps and interstices that exist within a narrative. Employing the first-, second- and third-person narrative techniques in her memoir- she reminds us that everything is straightforward and complex, self and other, revealed and concealed (Prabhu). For Prabhu, the only way to view her life is to see it as a prism, to let the light flow through different angles that make the emotional cores luminous, “If I had to tell it again, I would do it like this” says Prabhu (66). Halfway through her narration, she suggests that re-narration is the only way of unfolding the events of her life which is indeed therapeutic for her. Re-narration allows Prabhu to gain a deeper understanding of the lived experience of her father

who lived with clinical depression. It is a powerful medium for building connections and fostering dialogue with her deceased father. For Prabhu, re-narration allows for creative and artistic expression, strategies for coping and healing, which offers her insights into resilience and recovery. Her bold narration of her battling her depressive episodes, love, and abuse vis-à-vis her father's story of depression, addiction and inability to cope, within the threshold of the family is illustrative of precarious and therapeutic storytelling which allows Prabhu to reframe her narrative in a way that is more constructive and forward-looking. It helps her shift the focus from the difficulties of depression to the possibilities of recovery and growth. One of the characters of the one-act play- W- suggests that sharing (one's story) is the only possibility of healing, letting go of the shame and trauma that accompanies it. The character 'W' further articulates that the more tormented the writer, the greater clarity in writing (Prabhu 67). In the course of narrating her story, Prabhu is anxious of categorizing her father's story into tidy explanations and quick versions, but these are the versions she remembers. In trying to unearth a trajectory of her father's life, she fails to unearth any traces of a pattern from her father's diary or her memory. As she describes a history of mood-swings in the family, the narrator writes that every time she retold her father's life story, there could be variations. She compares her fragmented childhood experiences to impressionistic paintings and she considers her father's life resembling the works of the late Turner- with emphasis to the intricate details, the effects. In her father's life, melancholy was not a phase but it had consumed him. Comparing her father's life to the works of the late Turner, known for his intricate details and emphasis on effects, further underscores the depth and complexity of her father's experiences with melancholy. The emphasis on intricate details suggests a careful examination of the nuances and intricacies of her father's life, while the focus on effects may imply a consideration of the broader impact of melancholy on his existence. She shifts her narration from describing her father's life to her own life. Her abuse at the hands of her tutor has debilitating effects on her

mind because she could not speak about it at home. The narrator writes that her father had the habit of flaunting his life, retelling it multiple times. As she writes:

SGM had a compulsion to retell his life many times. Each time he tinkered with the telling; it was a recasting of his life too. His life was his material and he flaunted it constantly. An audience was never lacking...His childhood was folded inside him, an origami in the making, and would stay folded. Like mine...My childhood is like a Monet oil painting- all details are there and yet not there. He is a late Turner- one rousing detail, the rest effect. (Prabhu 72-73)

Prabhu writes that her father's story is difficult to tell because she could never fully comprehend his enigmatic life. She writes that their stories are quite dissimilar in certain respects but also similar in certain cases. Her father suffers from inferiority complex because he was not able to perform well at his workplace. This compels him to seek voluntary retirement since her father believed he was a morally upright person (Prabhu 74). His inability to cope made him long for death. As a witness to her father's transition, she struggles to recall the events because she spent most of her life suppressing the growing emotional rift in her mind. She recounts an incident at the Delhi based NGO for women in distress, where she was unable to share her story with her fellow audience:

I tried to join in even though I was like a baby tortoise growing a shell, but learning how brittle it turns with each recollection. She is the only one in the group who is not interested in sharing her stories with others. She knits, and knits constantly, her eyes on the moving needles at all times. Other women in the circle look at each other, take turns to speak, but she does not look at us, not even when we are sharing brutal stories.

(Prabhu 77)

She understands the pointlessness of this endeavour. Spending many years in Delhi, she finds herself navigating the same labyrinth of sorrow that her father had endured for most of his life. When she begins to write, she recognizes the inadequacy of memoirs that can only capture the pain experienced by families. Despite her initial decision not to write a memoir, she ultimately decides to do so, driven by the connecting thread that ties their experiences together—

depression. She describes depression thus: “all you have is a clinical diagnosis, some pills and a few words to describe the indescribable, all of which evaporate rapidly in the face of ‘be positive’, ‘get exercise’, ‘be strong’ ‘move on’ and the unspoken urgings to act like it never happened. The appearance of normality becomes crucial” (Prabhu 82). She further writes that the depressed mind has the propensity to evade answering questions about its precarious state.

She writes:

The biggest hurdle is that the mind that is unwell and needs treatment will do its best to talk you out of it. No other organ in your body is capable of this- the failed kidney will not articulate its denial. But the mind, even when it is rapidly sinking, will convince you at regular intervals that it is actually not so ill and that it is capable of recovery without intervention. The story of long-term depression often swings between these poles- denial and relapse. (Prabhu 83)

She imagines the possibility of having a conversation with her depressed mind on the pretext that none of the details of their conversations will be divulged. The narrator stresses the creation of a community of people living with a long-term mental illness. She points to the futility in trying to ‘help’ the depressed person, because it cannot be done, as “one has to have walked this land to appreciate the terrors of its topography- the unrelenting isolation, thoughts that spin in concentric circles, a listlessness that descends on every thought and situation, and a mind that is perfecting the art of naysaying and self-loathing” (Prabhu 83). In the section, “The Long Dying,” the narrator discusses her profound connection with her aging and ailing labrador named Chinna. As Chinna’s life draws to a close and the narrator grapples with a sense of powerlessness, she begins to perceive her father’s presence in the dog. During its early years, Chinna served as a reliable and compassionate companion, providing comfort and support during the narrator’s periods of severe depression (Prabhu 85). Much like the narrator’s father, Chinna is diagnosed with a terminal illness, which shuts down her kidneys leading to her death. Subsequently, the narrator is diagnosed with clinical depression by a psychologist, marking the

onset of a personal journey towards self-discovery and the potential for improved mental health. Throughout this challenging period, her loyal dog remains a steadfast source of solace and companionship. The immediate crisis the narrator confronted is the deterioration of her marriage. Experiencing a sense of entrapment, she resorts to medication, which leads to a profound feeling of physical and emotional confinement (Prabhu 94). Ultimately, she made the difficult decision to end her marriage and turned to writing as a means of coping, albeit with heightened episodes of anxiety. The narrator observes that depression transcends spatial boundaries and does not conform to simplistic notions of clear beginnings (Prabhu 98). As she writes:

Such is the illness that it seems to warrant silent suffering, as much as the silent moving on. If you were supine on a hospital bed, if your limb was in a cast, if you had a large bandage around your head, if you walked around with warts all over your body, you could claim illness, pain and suffering. With depression, all you have is a clinical diagnosis, some pills a few words to describe the indescribable, all of which evaporate rapidly in the face of ‘be positive’, ‘get exercise’, ‘be strong’, ‘move on’ and the unspoken urgings to act like it never happened. The appearance of normality becomes crucial. (Prabhu 128)

Her separation from Chinna after her divorce takes a visible toll on her mental health. The idea of dying without finishing her manuscript preoccupied her. Soon after, she is awarded a teaching assistantship for pursuing doctoral degree in the United States, and since then, she decides to look at depression as a “fellow traveller in an adjoining berth on a long train journey”. She engages in a dialogue with her depressed mind which only she and her mind could understand:

...they sized each other up, they talked tentatively, they stayed wary and affable at the same time. She felt its breath on her nape when she took long walks through the tall grass prairie, when she was cooking elaborate feasts entirely for herself in her little kitchen, when she learnt to dance the tango, when she sang in languages nobody around



her could understand. Between her and depression were the kinds of boundaries that lovers in new relationships valiantly try to put in place. (Prabhu 165)

In the whole corpus of depression and recovery narratives, the self is seen as capable of re-fashioning and re-positioning itself in terms of their experience, but not of authoring one's life. As Paul Ricoeur puts it aptly: "We learn to become the narrator of our own story, without completely becoming the author of our life" (71). Along a similar vein, Prabhu's memoir is a faithful exposé of the inner recesses of her life. Depression, as an outsider, which had, for years eluded understanding, but Prabhu attempts to manage, quite evocatively, to bring it within the realm of comprehension. In 'A Healing Art: Therapeutic Dimensions of Autobiography', (1990) Marilyn R. Chandler proposes that 'to be healed we seem to need to find a way to tell our stories' (4). She argues for the therapeutic function of narrative, and of autobiography in particular. Healing is linked with story-telling historically, and across many cultures. Many modern auto-biographers have written as a form of self-therapy, and the 'writing cure' – writing one's own life narrative– has been used as a systematic form of psychotherapy (9). Chandler identifies four therapeutic functions of self-narrative: catharsis (cleansing through confession), externalizing problems by telling the story, integrating chaotic experiences into a meaningful pattern for restoration, and fostering connectedness with the wider community. In her memoir, Prabhu delves into her personal experiences and emotions, including her struggles with depression, a depressive parent, the breakdown of her marriage, and her connection with her dog, Chinna. This self- exploration is a therapeutic process that allows her to better understand and come to terms with her feelings and experiences. Her narrative highlights the challenges and stigma associated with depression and mental health issues. By sharing her experiences, she helps normalize these struggles and encourages others to seek help and support. Prabhu emphasizes the importance of creating a community of people living with long-term mental illness. This can be therapeutic for both the narrator and others who may feel less isolated and

more understood when they find a sense of community and shared experiences. Prabhu describes how she turned to writing, walking, cooking, dancing, and singing as coping mechanisms. These activities serve as outlets for her emotions and ways to manage her mental health. Sharing these coping strategies can provide inspiration and hope to others facing similar challenges. the transformation of the narrator’s perspective on depression and her journey towards self-discovery.

### **Narrativizing madness and memory in Swadesh Deepak’s *I Have Not Seen Mandu***

Swadesh Deepak is an Indian playwright, novelist and a short-story writer. He is one of the seminal figures of the Hindi literary scene since the 1960s who is best known for his play *Court Martial* which appeared in 1991. *I Have Not Seen Mandu* originally appeared in Hindi as *Maine Mandu Nahin Dekha: Khandit Jeevan Ka Ek Collage* in 2003 which was later translated to English as *I Have Not Seen Mandu* by Jerry Pinto in 2021. Deepak mostly shied away from the limelight and was indifferent to all the fame that came his way. He has been living with bipolar disorder for over sixteen years. He went out for a morning walk in 2006 in his hometown Ambala never to return. The view of Chitra Harshvardhan on translation aptly fits the translation of Jerry Pinto. Harshvardhan holds that, “translation can also subvert the dominant mainstream use of language by deliberately using a disruptive style: the unconventional use of orthography or neologisms, the innovative usage of metaphors and images, of archaisms, of changing the syntax a little, compounding words innovatively... The idea is to experiment with language, challenging the hegemony of the dominant norm in language usage to signal resistance...” (41). In Swadesh Deepak’s memoir, the fragmentation and the impossibility of

attaining a unified-self contribute to the narrative psychosis<sup>15</sup>. This is also not to dismiss or ignore the suffering and trauma that psychosis may cause or inflict. The disruptive style mentioned by Chitra Harshvardhan, including the unconventional use of orthography, neologisms, metaphors, images, archaisms, and changes in syntax, may be aligned with the narrative structure of Deepak's memoir which tries to narrativize intricate and often indescribable aspects of mental health challenges. It allows for a more nuanced and personalized expression of the experiences, resisting the limitations of conventional language and enabling a more authentic portrayal of the psychological complexities involved. Deepak's memoir describes his seven-year long battle with mental illness. Deepak writes that body that his soul had tried to abandon many times does not have any memories. He writes that, "...memory lives in the soul and the soul is immortal" (43). So, according to the writer, the book is a poignant assertion of his soul. The memoir diverges from the Hindi version in that Pinto adds the word 'perhaps' which suggests the inability and impossibility to remember traumatic experience of mental illness, the borderline between sanity and insanity, between body and the soul, between dreams and reality. It also opens up numerous possibilities for the reader to interpret the memoir. Deepak vehemently asserts that "there is no method in this madness" hints at the possibility of the non-linear, stream-of-consciousness like structure of the memoir (49). Deepak's style reflects the inner workings of the mind in a more spontaneous and unfiltered manner. Therefore, his assertion "there is no method in this madness" implies that the memoir may unfold in a way that mirrors the unpredictability, complexity, and eschews

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<sup>15</sup> In *Writing and Madness: Literature/Philosophy/Psychoanalysis*, Shoshana Felman explores the relationship between writing, madness, and psychoanalysis. She does not specifically use the term "narrative psychosis" in this context, but she does discuss the ways in which literature can be seen as a form of response to trauma and as a way for individuals to grapple with the complexities of their experiences. Her analysis often delves into the intricate connections between language, identity, and psychic trauma. She contends that literature provides a space for the expression of the unspeakable and the exploration of the unconscious. Felman draws on psychoanalytic concepts to analyze the ways in which writers use narrative as a tool for understanding and representing their internal struggles (Felman, emphasis added).

a straightforward method. In the translators' introduction, Pinto writes that Swadesh Deepak's *Maine Mandu Nahin Dekha: Khandit Jeevan Ka Ek Collage* is a first-hand account of the writer's descent into madness and his return. In the opening section of the book- "There is No Bridge Here", which serves as an introduction, Deepak holds the character- *Mayavini* – a woman, as well as a metaphor mirroring his distressed emotional state, responsible for much of his sorrows; someone who had transformed his life completely.

*Mayavini* has hammered a nail into my head. I found out later, very much later. My world went from glorious technicolour to monochrome, diseased and ugly. My river was lost. There was no bridge for me anywhere. For about seven years, I was the prisoner of mental illness. Those who suffer from this disease have terrifying dreams and their responses are violent and full of hate. At worst, strangers attack you as do the people who know. The latter give you no support or encouragement. The mentally ill are branded by society.

(Deepak xvii)

In the above quoted lines, Deepak describes a traumatic event involving *Mayavini* hammering a nail into their head. The revelation of this event comes later, suggesting a delayed awareness or understanding of the gravity of what happened. The shift from "glorious technicolour" turning into "monochrome, diseased, and ugly," conveys a profound shift in the author's perception of the world. This shift likely represents a transformation from a positive and vibrant outlook to a darker, more troubled state. Deepak confesses that he has been living with a form of mental illness for over seven years. He initially spends a few months at the Post Graduate Institute of Medical Education and Research, Chandigarh as a patient and the most tormenting period of his life begins after his release from the asylum. Soon after he is released, Deepak wrote a play *Sabse Udaas Kavita* ('The Saddest Poem') but it is difficult for him to write about his experience of mental illness. The writer calls his narrative a "soul-memoir-a fractured one"

and he cautions that it should not be confused as a piece written for a medical journal. He also describes the difficulty of finding a right idiom for narrating one's sorrows. As he writes:

Since memory came in flashes, I used the collage mode, juxtaposing various time zones. For all the years that my soul was in chains, I was addicted to the speaking of English...There is much more to write. I abandoned this midway. How long can one talk of one's sorrows? The dark shadow of this disease never completely evaporates. My dilemma is best summed up in Horatio's words after Hamlet's death: The rest is silence. (Deepak xviii)

By invoking Horatio's words, Deepak is likely tussling between a resignation and acceptance in the face of his own struggles with his mental illness. He acknowledges the limits of language to capture the intensity of his emotions. In the article, "Madness and Inadequacy of Language in Swadesh Deepak's 'I Have Not Seen Mandu', Abheet Srivastav writes, "the terrain of the narrative itself jumps between reality and illusion. The lines between internal and external drama are often blurred. We move from the internal chaos to an external stasis. The temporal and spatial tie into each other, as we jump between time and space, or are stuck in an elongated moment that refuses to pass" (Srivastav). Swadesh Deepak's varying mental conditions and his paranoia, I suggest, prompts a new mode of writing altogether. Such a style of writing does not exclude or dismiss lived experiences as meaningless or illness as an anomaly to be treated. According to Shoshana Felman, "what madness narratives achieve (when authors overcome the self-perception of being unreliable due to their insanity and produce texts seen as sane.) is to narrativize and [visibilize] a previously-denied voice" (3-4). As a result, each such text "continues to communicate with madness – with what has been included, decreed abnormal, unacceptable, or senseless – by dramatizing a dynamically renewed, revitalized relation between sense and nonsense, between reason and unreason, between the readable and the unreadable" (Felman 5). Felman's view aligns with Deepak's narrative in the sense that he

employs various metaphors and imageries which enable the reader see the world from the perspective of a person who is on the crossroads of sanity and insanity. In the first chapter, “A Late Night with Nirmal Verma”, the narrator attends an all-writer’s meet-up at Sheila Sandhu’s house and he narrates the story of his seven-year imprisonment at the mental health facility which made him lose his grip on language. He writes:

I had spent seven years in a dark deep pit. Slowly I had forgotten how to use language. But I kept chatting to the darkness; in the language of the darkness. A soul in a constant state of unrest learns strange, unique languages. These words are not to be found in any dictionary. (Deepak 1)

Deepak creates in his narrative what Charlotte Baker calls ‘textual psychosis’<sup>16</sup> through use of literary techniques and structural devices, which demonstrates psychosis at the structural and formal level. So, Deepak not only writes about psychosis or his mental illness, he writes psychosis. Through Deepak’s reference to inaccessible allusions, repetition and fragmentation, he seems to psychoticize the memoir. His memoir replicates at the level of form the chaotic and disordered mental condition of the author. Deepak further talks about his loneliness and abandonment by his family members during his years at the mental hospital. During the seven years, he lives a subterranean existence (Deepak 4). In the memoir, the hallucinatory narrator feverishly alternates between the past, present and the future: between his first encounter with his seductress or *Mayavini*, as he calls her, and his time spent in the mental hospital and the ICU. He repeatedly tells the story of his first meeting with the seductress in an effort to stress the mental and physical decline of his body and his creative abilities stressing on the embodied

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<sup>16</sup> In “Reading Psychosis in Kathy Acker’s Writing: Rethinking Clinical and Critical Perspectives”, Charlotte Baker argues that “Acker’s contextual, textual, and experiential representations offer a version of psychosis that is meaningful and ‘understandable’, subsequently offering clinical insights that prompt rethinking of contemporary clinical and critical views. In her thesis, Baker observes that reading psychosis in Acker’s work can lead to new ways of learning about and working with people which support the need for new ways of acknowledging and understanding psychosis, ways that a dominant biomedical perspective on mental health does not always sufficiently recognise.” (Baker)

nature of his condition. Rita Felski uses “the concept of ‘deep intersubjectivity’ to refer the representation of persons as embedded and embodied agents” (9). Felski’s concept of deep intersubjectivity provides a lens through which to understand and appreciate the nuanced and layered portrayal of mental illness in Deepak’s memoir. It underscores the interconnectedness of personal experience and the broader social context. As Deepak’s narrative unfolds, the formation of the self is reliant on how it is perceived by the other within the self as well as the perception of otherness by the self. Deepak’s memoir foregrounds non-linearity, fragmentation and trauma which can enable one to think of different approaches of interpreting life-writing and mental illness. Following his return from the hospital, the narrator is afraid of light and everything appears horrid. As he writes:

Faith can also be eroded when the body is being stimulated through the modern medical machinery. Your body flies up three feet in the air when you’re given electric shocks. This ‘encouraging’ advice marks the giver as an outsider. For me everything had become frightening, disgusting- in a word, macabre. (Deepak 2)

Although his friend Vikas urges him to meet his fellow writers, the narrator is still in the past and struggles to come to the present. After his arrival in Delhi, the narrator is *reminded* of his encounter many years back with a seductress or *Mayavini*, and holds her responsible for his current state. The narrator then recalls that period of seduction by that woman who had taken all the powers of writing and language from him (Deepak 9). However, the meaning of *Mayavini* is left ambiguous- is it a real woman or a metaphor of his mental illness itself. The narrator describes it thus:

I thought she was goading me. Every afternoon she would visit me in the bedroom and in the next seven years she would tame me. How could I know that she could disembodily herself? First she took language from me. Then my pen. Then my right hand died, the hand in which I hold my pen. I was disarmed, defenceless, but not yet defeated for the doctors could not find the disease. I knew the enemy. (Deepak 9)

Deepak paints a vivid picture of the multifaceted impact of *Mayavini* in his life—physically, mentally, and creatively. It conveys the gradual erosion of his abilities and the challenges he faces in the face of an elusive adversary, which adds to the complexity of his experience with mental illness. In “I Have Not Seen Mandu,” Swadesh Deepak portrays himself as a victim of mental illness and its consequences. However, despite this portrayal, the narrative agency of the author can still be identified within the text. Firstly, the act of writing itself demonstrates a form of agency. Despite Deepak's struggles with his mental health, he is still able to articulate his experiences, thoughts, and emotions through his memoir. This act of self-expression and self-reflection indicates a degree of agency as he asserts control over his narrative and attempts to make sense of his experiences. Additionally, Deepak exercises agency in the way he frames and interprets his own story. While he may depict himself as a victim of circumstances, his choice to share his narrative with others and to explore the complexities of his mental illness through his writing reflects a sense of agency. He is actively engaged in shaping the narrative of his life and reclaiming his voice despite the challenges he faces. Furthermore, I maintain, the ambiguity surrounding the character of *Mayavini* suggests a level of agency in Deepak's narrative choices. By leaving the interpretation of *Mayavini* open to question—whether she is a real woman or a metaphor for his mental illness—Deepak invites readers to engage with his story on multiple levels and to draw their own conclusions. This narrative ambiguity demonstrates Deepak's authorial control and his ability to craft a narrative that challenges conventional interpretations of mental illness. Overall, while Swadesh Deepak may present himself as a victim in *I Have Not Seen Mandu*, his narrative still embodies elements of agency through his act of writing, his framing of his own story, and his narrative choices. Apart from describing the musings with the literary circle, the narrator of Deepak's memoir also describes the Hindi literary scene in general. They discuss and compare the literary works of the circle of writers gathered at Sheila Sandhu's place. The narrator believes that it was during his journey



to Delhi that he had his first hallucination- an encounter with *Mayavini*- a spectral presence which continues to haunt him in the present. During his conversation with Nirmal Verma, the narrator confesses that the onset of the disease can be ascribed to the night of the performance of Court Martial. He writes:

Nirmal: Swadesh, did you feel the onset of the disease?

I didn't know of it but I received two warnings: one in English and the other in Hindi. In that big city, it was the first night (a mischievous way of saying the opening night) of *Court Martial*. (Deepak 17)

The narrator seems to be in a reverie as he fails to find a correct idiom to answer some of the simplest questions put forward by his friend- Verma.

How could I tell him? Why would I? The words are tough, obstinate. My appearance is different, my words are different. If the right words do make their way from my belly to my throat, they get stuck somewhere behind my clenched teeth. I, the talkative one, was alone. I, Swadesh, from whom a river of words once flowed. She killed my right arm, my right hand, with which I held my pen, with which I tied my pyjama cord. If... if... if... (Deepak 19)

During the conversation with his fellow authors, the narrator's mind frequently blurs the distinction between perception and reality. Deepak constantly alludes to other literary works of Hindi and English literature in order to justify the veracity of his claims. After patiently listening to his sad plight, Nirmal Verma opines:

Nirmal: Why is it necessary to write? Can a book ever be bigger than life? Life is God's creation and nothing we create can be bigger than it, certainly none of the books we write. Every book has only one dominant colour. And life- it changes colour so often. Keats called it a chameleon. Light and darkness, joy and sorrow, laughter and tears, life is ever changing. How could a book ever be bigger than it? (Deepak 29)

Deepak reflects on the limitations of language in capturing the variability of life, especially when it comes to intricate experiences as mental illness. There are occasional musings on what constitutes creativity, the process of artistic creation and the author's ideas on life and the merit

of a literary piece. Nirmal Verma further notes that in order for an author to create, they have to live with one's characters for many years, partaking their joys and personal sorrows. One has to bleed with them and accept damage (Deepak 29). Deepak's writing constitutes a series of unrelated fragments, sections repeated from his other works, intertextual references and interior monologues. In the next chapter, "I Have Not Seen Mandu", the narrator describes the story of his first encounter with the *Mayavini* who says "I Have Not Seen Mandu" after watching the performance of the writer's play Court Martial. The narrator describes her thus:

As she spoke, by chance, I saw her teeth flashing as bright as stars in the sky. I was on full alert. I looked at her with attention for the first time. I was reminded of the heroines of the former poets...I looked at her, really looked, for the first time. The sun had risen in the night. The embodied sun, in the form of a woman. (Deepak 32)

The narrator recounts during the course of his stay at the mental health facility, he was reluctant to describe his case to the doctor as he felt that the act of losing his creative powers was similar to losing his masculinity. He writes:

...He would have read my history and he would know that someone had stolen my words, left me dumb, an obstinate dumbbell. To tell the doctors anything would be to ruin my pride. A he-man. A he-man who has lost his powers. They belong to Mayavini now. Swadesh has nothing left. (Deepak 41)

The narrator sees his creative powers as symbolic of his masculinity. Losing this creative ability, in the narrator's perception, becomes synonymous with a loss of masculine strength and prowess. He is hesitant to talk about his illness to a friend who is a press reporter from the Indian Express because he fears the possibility of exposing his illness to his friends and followers. So, there are lucid moments in his memoir when Deepak tries to objectify his illness. Deepak writes: "How could I tell Niru that I had encountered such destructive beauty? That it had already taken me captive. That it had turned Swadesh Deepak, the born enemy of fiery beauty, into a bed-ridden shadow of himself?" (Deepak 42). When he narrates his experience

of meeting the seductress with the doctors, the narrator alludes to several popular works of literature- such as Shakespeare's lines from Othello ('So fair was never so fatal instead' of 'So sweet was never so fatal') and his riffing of Ophelia's famous last lines from the play- Good night ladies, good night, sweet ladies, good night good night' which is ironic when the narrator says 'Good night Dr Partha Choudhury, good night everybody' (Deepak 43) because he is in a subliminal state at the mental hospital which could be a function of his failing memory. Deepak's reinterpretation of Shakespeare's famous lines may serve as a symbolic means of communication with his doctors allowing him to convey complex emotions without directly articulating them. He personalizes the literary references, the use of irony and challenges he faces while communicating with his doctors. During his years of stay at the mental institution, his memories begin to fail and he begins to doubt his creative abilities. His encounter with the seductress had turned him into a 'mental cripple' (Deepak 66). From a physical manifestation, the seductress takes the form of a spectral presence in the writer's life even when she is not physically there. She becomes an 'internal seductress' (Deepak 71), a disturbing presence which continues to haunt the writer during the years of exile and imprisonment at the mental institution. During one of his sessions with a doctor at the institute, the doctor tells the narrator that mental illness remains a taboo and there is no 'social sanction' regarding the disease. As he says:

Avneet: ...There is no social acceptance of this disease in our country. No social sanction. When they see someone in rags and in filth on the street, first the children and then the adults pick up stones to throw at them. And we become barbarians. Total barbarians. (Deepak 77)

According to him, his illness had created an impasse within himself. When the narrator describes his inability to write to the doctor, the doctor exclaims:

Swadeshji, you know that writing does not happen just because we want to write. Your interior world lies in ruins. When some people finally come to settle there, they will begin to write for you. But it will take time. (Deepak 88)

On a separate occasion, his doctor observes, “In our country, cancer has found acceptance, even AIDS is now acceptable, but the mentally ill are not” (Deepak 122). There is no ‘method in his madness’, (Deepak 124) the narrator acknowledges to his son Sukant, describing his wife’s changed temperament because of her refusal in accepting her husband’s deplorable condition. The narrator’s present emotional condition affects his writing and he suffers from a perennial writer’s block. He seems to exist in a void. He says that languages have begun to turn away from him and his time has been castrated (Deepak 91). The narrator writes his friends from the Hindi literary circle encourage him to write about his experience with his illness which “many creative people have battled with...” (Deepak 118). When the narrator retains serious injuries following a burn, and the doctor informs him that he would spend the rest of his life as a vegetable (Deepak 124). At times, the pages of the narrative are often rendered incomprehensible when the narrative voice abruptly shifts from the present to the past. In the chapter, “Do I Know You?”, the narrator frequently uses the image of the rainforest to describe a dreamy and surreal world inhabited by him and the seductress or *Mayavini* or *Kaamna* as he calls her. During his stay at the hospital following the grievous burn injuries, the narrator’s loneliness and isolation compels him to construct an alternate world. His paralysis undermines his ability to write. He loses his grip over the real world and does not seem to have a fertile imagination anymore. However, the *Mayavini* which is possibly an embodiment of his desires and creative potentials, other than the real woman- *Kaamna* he encounters at the premier of his play, continues to haunt him in his dreams. The narrator eventually starts losing confidence in his writing abilities and feels that he has not achieved anything in life other than a crippled brain with no liberation (Deepak 197). From a reading of Deepak’s memoir, “Mayavini”

represents a complex and multi-layered metaphorical entity rather than a literal hallucination or a concrete person. *Mayavini* embodies various aspects of Deepak's inner turmoil, desires, and creative potential, serving as a symbolic figure that haunts his thoughts and dreams. Firstly, *Mayavini* can be interpreted as a representation of Deepak's mental illness itself, particularly his bipolar disorder. Throughout the memoir, *Mayavini's* presence is associated with feelings of fear, confusion, and a gradual loss of control over his life and creative abilities. Her spectral presence in his dreams may symbolize the persistent struggles Deepak faces in managing his mental health and the intrusive nature of his condition on his everyday existence. Additionally, *Mayavini* may symbolize Deepak's unfulfilled creative aspirations and the challenges he encounters in pursuing his artistic endeavours. As the narrator recalls *Mayavini's* gradual disempowerment of him—taking away his language, his ability to write, and eventually his confidence in his own abilities—it reflects Deepak's internal struggles with self-doubt, creative blockages, and a sense of inadequacy as an artist. Moreover, *Mayavini's* contrast with the real woman *Kaamna*, whom Deepak encounters at the premiere of his play, highlights the dichotomy between fantasy and reality in his life. While *Kaamna* represents a tangible connection to the external world and potential for human connection, *Mayavini* embodies the internal conflicts and psychological barriers that hinder Deepak's ability to fully engage with reality and find fulfillment in his relationships and creative pursuits. Overall, *Mayavini* serves as a richly symbolic and enigmatic figure in Deepak's narrative, embodying his inner demons, creative struggles, and existential dilemmas. Through *Mayavini*, Deepak grapples with the complexities of his own psyche and the profound impact of his mental illness on his identity, relationships, and artistic endeavours. He opines that:

I experience things that are beyond my ego and my reality. Bad health, a disorder in the heart and mind and a sense of grandeur. It's an arbitrary and directionless weirdness.

Then the 'I' so precious to individualism experiences radical changes in thought and feeling. (Deepak 198)

The narrator seems to hint at the possibility of a gap between reality and visions of grandeur which is because of his narcissism and megalomania. Although the narrative strands in the story are disjointed and often unreliable, there are sections in which the narrator tries to cohere these fragments into something meaningful and useful. The fragmented narrative embodies the nature of the psychotic experience. The narrator is in a constant search for his self and is always in the process of becoming when he says:

Who am I? A constant search for meaning and relevance. I believe only that about myself which I wish to believe. I do not even look for proof. Our best-loved beliefs suffer no criticism. We look for no evidence for them. Thus, fleeting reality is easy. Easier than confrontation. Which is why my *Mayavini* is a paralysis brought by the wind. (Deepak 211)

Deepak encapsulates the internal struggles and coping mechanisms of an individual grappling with mental illness. It touches on themes of identity, belief systems, and the complex interplay between reality, perception, and the avoidance of confrontation—a poignant reflection on the psychological challenges inherent in living with mental health issues. The reference to *Mayavini* as a “paralysis brought by the wind” adds a symbolic dimension. *Mayavini*, possibly representing the mental health struggle, is portrayed as a force that induces a form of paralysis—perhaps a sense of inertia, stagnation, or helplessness. The narrator seems to have a strong death-wish since he feels that the entire world has turned hostile towards him because of his apparent mental instability. He has lost control of his emotions and abilities and his body seems to have started conspiring against him (Deepak 200). During his stay at the psychiatric ward and even after his release, the narrator has a recurrent fear that his audience would not read his work because of his perennial illness. The narrator wonders whether his ‘diseased dreams’ gave rise to the seductress that comes to haunt him during his stay in the asylum. Deepak’s prose is marked by its emotional intensity, his willingness to share personal

intimacies with the reader, the use of metaphors and vivid imagery throughout the text, and his explicit efforts to encourage the reader's understanding. These elements collectively serve as his attempts to find meaning in his illness and to construct a narrative that helps him make sense of his experiences. At one point in the story, the narrator imagines being with *Mayavini* beyond the real world:

...I am in the shadow of every light. I am the Hamlet of my age. Is your existence a trick? Only an illusion? We will live in a cave. We will have no desire to know anything. We will sing the old ballads to each other... Outside our cave, the wind will carve out maidans for us. Even in that darkness, we will be able to see each other...I will begin some long stories...The language of the body admits of no grammar. (Deepak 219)

Deepak's assertion that "the language of the body admits of no grammar" implies a preference for non-verbal communication. This might suggest a recognition of the limitations of verbal language in expressing complex emotions or experiences associated with mental health. Along the lines Gayathri Prabhu, Swadesh Deepak's memoir make ethical and emotional claims on their reader and the narrator's feeling of radical estrangement. Deepak's act of creating or engaging with literary narratives serves as a therapeutic process for his radical estrangement. In other words, the process of writing or reading literature through its healing or transformative effect can help individuals bridge the gap between themselves and their surroundings, find solace, or gain insights into their experiences of estrangement. It suggests that storytelling, through its ability to connect with the human experience, can have a healing or transformative effect on those who feel radically estranged. Deepak suggests that there is a symbiotic relationship between feelings of estrangement and power of literary narratives to alleviate the feelings of distress and turmoil. The apparent non-linear and disjointed structure of the narrative or Swadesh Deepak's attempt at psychoticizing the narrative offer an instance of how people experiencing inner confusion, paranoia and hallucinations have a kernel of reasoning

left in them and they have the ability of narrating experience of mental illness and complicate what constitutes the narrative self in self-written accounts such as the memoir.

**Exploring Mental illness, addiction, and identity in Shreevatsa Nevatia's *How to Travel Light: My Memories of Madness and Melancholia*: A journey through trauma, recovery, and self-discovery.**

Shreevatsa Nevatia's memoir, *How to Travel Light: My Memories of Madness and Melancholia* was published in 2017 and it attempts to humanize the condition of a person living with bipolar disorder. His narrative, as the author asserts is "not a story of survival, of beating the odds or of forbearance" (iii). The only heroes in this story, the author stresses, are the members of his support system. Sidonie Smith had asserted that the act of narrativizing one's life involves "agonizing questions of identity, self-definitions, self-existence, or self-deception." (12). Smith's observations seem pertinent to an understanding of one's life caught in the ebb of a debilitating mood disorder such as manic-depressive illness or bipolar disorder. The questions which seem to arise include, among many others, what memories should the person ignore and which memories should a person include in his narrative, how much knowledge and reasoning capacity does a person living with mood disorders have. Questions such as these and many others have troubled psychologists, psychiatrists and researchers, albeit in different ways. In this section, I intend to examine Nevatia's memoir by exploring the intricate relationships between the self, language, and mental health disorders as avenues for embodied knowledge. I will also delve into how the process of writing the memoir can serve as a therapeutic and cathartic experience, challenging and complicating conventional perceptions of the mental health disorder. In his article, "A Pause in My Meteor Showers" (2016) which appeared in the Open magazine a year before the publication of his memoir, Shreevatsa Nevatia recounts his



experiences of institutionalization at the asylum. His memoir employs various mental imageries and metaphors to develop a new notion of embodied experience as something which is fluid and transformative. Nevatia finds solace in the act of writing as it serves as a cathartic release for his traumatic childhood experiences. His memoir offers a compelling narrative of his challenging adolescence marked by abuse, and the subsequent journey towards recovery from the lingering scars of those traumatic memories. In narrating the story of his trauma and mental illness, Nevatia seeks to find an adequate language or idiom to describe his liminal experience- pain, madness, the threat of the erasure of the self, self-loathing and annihilation. He employs metaphors to offer diverse interpretations of the illness experience, moving beyond a straightforward sickness-to-recovery narrative. In Nevatia's memoir, the emphasis is not on the kind of diagnosis or mode of treatment prescribed but on the act of telling one's story as an empowering exercise. Ellen Siegelman and Marilyn Chandler have observed that "the power of the metaphor for expressing liminal experience lies in its hybrid and multilayered associations" (Siegelman and Chandler quoted in Brooks). In *The Invading Body: Reading Illness Autobiographies* (2007), Einat Avrahami explores "terminal illness narratives in relation to embodiment and subjectivity, and writes that the limitations of our assumptions about the terminally ill are exposed when the writing subject is terminally ill" (4). Avrahami observes:

Terminal illness narratives and photographs alert us to the problems that arise from treating historically specific bodies as textual, and rather passive, surfaces whose meaning is determined by social institutions and discourses. They question the prevailing poststructuralist perspective that has generated neat formulations of materiality, and of the body, as always already a discursive construct, the product of conscious or unconscious political inscription. (5)

Avrahami's argument can be further extended to include subjects who are living with a debilitating mental illness or physical disability. She challenges the view that ill bodies are "mere embodiments of the normative discursive system and highlights the interrelatedness and

inter-constitutive dynamics of embodied experience and discursive constructs” (Avrahami 12). Nevatia believes that writing about his mental illness in the form of a personal narrative will help him negotiate his illness. Nevatia’s narrative distinguishes persistent mood swings and distress from everyday sadness. The “crash” enables him to follow his impulses which disrupts many years of his life. In the preface, Nevatia writes thus:

Of all the delusions that mania conjures, I find one is more enabling. I feel I remember everything. At any point, memory is at best a collection of fact and some fiction, but when I am manic, even my inventions start to seem persuasive. A psychotic subject is at first an unreliable narrator. Though modern fiction dictates that truth is relative, depression, which invariably follows a manic spell, leaves me lumbering with guilt. (Nevatia 13)

Nevatia reflects on the impact of mania on his perception and memory. He suggests that during a manic episode, he experiences a heightened sense of recall, feeling as though he remembers everything. The crucial point is that during mania, the author’s inventive thoughts become exceptionally persuasive, blurring the line between reality and fiction. He describes a manic subject as an initially unreliable narrator which could hint at the heightened creativity and persuasive nature of thoughts during mania may lead to a distorted version of reality. Nevatia’s mention of depression following a manic episode introduces a contrasting state, suggesting that the euphoria of mania is followed by a more somber and reflective period. His reference to feeling “lumbering with guilt” implies a sense of remorse or burden associated with the aftermath of the manic phase. Nevatia highlights the complex interplay between manic states, memory, creativity, and the emotional consequences that follow. Through the narrator’s non-linear process of narrating the story of his struggle with his body and mental illness, he reveals the various elements of his embodied narrative- griefs, unexpected repercussions, and, ultimately, self-understanding. Kay Redfield Jamison’s *An Unquiet Mind* (1995) is perhaps the most well-known book on mood disorder, which describes the writer’s struggle with her mental illness. I draw inspiration from the term “language of madness” as used by Jamison in her

autobiography, where she highlights the role of written words in influencing our perceptions of mental illness. In his memoir, Shreevatsa Nevatia strategically employs the word “madness” to depict the diverse experiences of living with mood disorders and, perhaps, to underscore the influence of language in shaping our understanding and dispelling myths about this condition. As mentioned earlier, crafting a coherent narrative during periods of mental health challenges can be a challenging endeavour. It entails solidifying past experiences, which may not have been the same as they were originally perceived (Jamison quoted in Purkayastha 34). While all auto-biographers and memoirists must grapple with these different parameters in order to construct a coherent narrative, this is more the case with people living with mental health disorders who seek to impose meaning into their lives by narrativizing their story. In the book’s preface, Shreevatsa Nevatia adheres to the common belief about individuals with manic depressive illness or bipolar disorder, stating that a “psychotic subject is an unreliable narrator” (1). However, Nevatia contradicts this notion by recalling vivid details from his experiences during periods of mania and mental turbulence. What distinguishes his narrative is his ability to recount the various phases of his illness without assuming the role of an authoritative figure. As Nevatia writes:

Confession is not an act of courage. It is more cathartic than it is brave. My purpose, if I had to find one, was to play, not pander. This memoir is not a story of survival, of beating the odds or of forbearance. The only heroes of this story are the members of my support system, who, despite my recalcitrance, have stood by me and have helped me find my feet time and again. (Nevatia 15)

Nevatia states that his purpose, if he had to find one, was to play and not pander. This suggests that he may not be writing the memoir for the sake of sympathy or validation but rather to share his experiences authentically. He states that the memoir is not a story of survival, beating the odds, or forbearance. This could be his way of distinguishing his narrative from typical narratives of triumph over adversity. Instead, he may be focusing on the ongoing process of

living with mental health challenges and the support he receives from his network. In ‘A Healing Art: Therapeutic Dimensions of Autobiography’ (1990), Chandler proposes that, ‘to be healed we seem to need to find a way to tell our stories’ (4). She argues for “a therapeutic function of the narrative and of autobiography in particular. The therapeutic function that Chandler identifies include catharsis, restoration, connectedness and transformation” (5). Tobin Siebers advances “a theory of complex embodiment which fuses parts of the social model of disability which views the environment and strictly disabling and limiting with the medical model of disability which situates disability within the individual body” (26). In Siebers’ words,

A theory of complex embodiment understands disability as an epistemology that rejects the temptation to value the body as anything other than what it was and that embraces what the body has become relative to the demands on it, whether environmental, representational, or corporeal. (27)

Siebers’ approach considers the situational reality of the body and what the body is in that social environment. Siebers’ approach could also suggest an acknowledgment of the changes in one’s mental state and an acceptance of those changes in response to various external and internal factors, such as environmental, representational, or corporeal demands which can be aligned with how Nevatia chooses to portray his internal struggles in his memoir. His approach appears to be useful in describing the nature of therapeutic storytelling in the three texts analyzed in this chapter. Nevatia’s memoir primarily explores how childhood trauma influences the mental health of an individual as they navigate periods of addiction, hallucination, and delusion. Nevatia strives to promote different ways of navigating and negotiating his illness, distinct from the commonly expected views of pity, sympathy and compassion associated with mental health conditions. Nevatia describes his bipolarity as a “condition which oscillates between mania and depression, from plenitude to isolation” (79). He describes his mental illness as a state of flux. However, these are not merely the dualities he describes. Instead, the narrator aims to problematize the medical model of bipolar disorders

which tries to impose a uniform pattern on individuals living with such conditions. While recognizing the material basis of mood disorders, Nevatia also believes that moods must be “interpreted”, even if only partially, to alleviate distress. Nevatia’s memoir seeks to explore how the act of narrativizing one’s experience of trauma and distress may have therapeutic benefits for the narrator. According to Nevatia, revealing one’s bipolarity is “more cathartic than brave” (xiii). He begins by tracing the memories of his childhood with his grandmother who dresses him up as Krishna. During his childhood, he internalizes every scene of Krishna in B.R Chopra’s *Mahabharata*, his curves, smiles and the ways the *gopis* used to gravitate towards him. After a series of amorous encounters with women, most of which are foredoomed to failure, he is drawn to cannabis and alcohol all the more forcefully. He is caught in an endless spiral in his unconscious mind and the sexual assault that he experiences at the hands of his cousin- Satyah- during his adolescent years, affects his mental well-being to an extent that he becomes an addict. The initial section of his memoir documents the phase of his life during which he is admitted to Starlight, a mental health facility that also serves as a rehabilitation center. This admission follows a period of mania and his involvement with cannabis. During one of his interactions with an inmate of the mental health facility- Shailesh- an alcoholic- we get to learn of his bipolarity and that he resorted to drugs and alcohol due to his inability to cope with his debilitating moods. He writes:

I revealed to him that, in 2007, I had been diagnosed as bipolar, and that cannabis had almost always driven me to madness. It was, however, the cheap alcohol at Bombay’s Press Club that, in January 2016, proved seductive. (Nevatia 4)

In his diary, the narrator keeps a record of the events that transpire after his admittance at the rehabilitation center. According to him, “addiction never forbade expression it only proved how violent one’s intent can be” (xx). Nevatia reconceptualizes his addiction habits as a “mode of recovery” (Nevatia 52) from his mental health issues. Nevatia dismisses the possibility that he

is subconsciously driven to addiction. He questions the idea about the notion of bipolar disorder and addiction being culturally constructed, especially when the psychiatrist assumes that his addiction was the catalyst for his manic-depressive illness as opposed to the other way around. He describes his stay at another rehabilitation centre, Fortune Foundation, which was run according to the principles laid down by Alcoholics Anonymous, after he is found in possession of drugs. In a series of conversations with the inmates, the narrator discovers that the reasons which drove them to addiction lay rooted in the family. Most of the mental health disorders were closely correlated with inter-personal relationships and not merely the genetic disposition of an individual. He acknowledges his drug addiction and confesses that persons with mood disorders are cornered because of their different mental constitution. In the essay, "Addiction got me what I needed: Depression and Drug Addiction in Elizabeth's Wurtzel's Memoirs", (2008) Joanne Muzak writes that, "in western culture both drug addiction and depression are referred to as "diseases", or "illnesses"-as pathological responses to, or at least reflections of, unbearable psychic pain...Drug addiction speaks more loudly than depression. The drug addict, is afforded by the possibility of recovery (and redemption) from the destigmatizing effects of western medicine" (98). Nevatia turns to drugs and alcohol in an attempt to reconcile with his bipolar condition. The idea of being an addict and a bipolar is used throughout the memoir not only as a trope but as a mode of embodiment through which the narrator comes to an understanding of his divergent selves. In his memoir, Nevatia communicates with his "other self" by resorting to various metaphors. His construction of selves is multifaceted—prior to and post manic depression. In his moments of mania, Nevatia experiences a sense of isolation from language, perceiving the world as a "cornucopia of possibility." Seeking rehabilitation provides him with a picturesque escape (Nevatia 15). Interacting with his fellow inmate Ishan, he learns that he, like the narrator, wants to make amends and rid himself of his addiction habits. The narrator confesses to him the first time he smokes marijuana is during his days in

Sussex, and drugs “become a gateway, his ticket to assimilation (initially)” (Nevatia 17).

During that phase, his creative potentials are at their finest:

The marijuana I smoked with my Prozac focused my mind. Studying literature and media studies, my curriculum included third-wave feminists, Freud and Foucault. I articulated my otherness in terms that were postcolonial and psychoanalytic. The joints I smoked, the cocaine I sometimes snorted and the magic mushrooms I ingested all sent me back to a room that was stuffed with books and A4 sheets of paper. I didn't have to have conversation. I could make them up. The fiction I wrote at the time, pages of unattributed dialogue, read more like scripts I'd written for theatre. (Nevatia 18)

Nevatia's references to using marijuana, cocaine, and magic mushrooms and retreating to a room filled with books and paper suggests a form of escapism. The substances served as a way for Nevatia to cope with his experiences, and the act of writing fiction is a means of creating alternative realities or narratives. His description of the fiction he wrote at the time reading more like scripts for theatre suggests a performative or theatrical aspect to his writing. This could imply a connection between his creative process, substance use, and a need for expression that goes beyond traditional prose. However, his grandmother's death and his heartbreak from his girlfriend during his adolescent years culminates in depression, and leads to his obsession over marijuana and Prozac. The narrator remarks that the Mental Health Care Bill of 2013 includes in its definition of mental illness all mental conditions associated with alcohol and drugs. However, mental health institutions can eclipse the repercussions of more profound disabilities (Nevatia 21). These institutions often view manic behaviour as a consequence of addiction, when it is often the other way around. He recalls a moment spent with his psychotherapist who often overlooks the narrator's version of his illness and what led him to addiction in the first place. Most of his therapists often prescribe medicines and suggest ways of letting go of it, which causes his manic behaviours. Contrary to what the doctors say, according to the narrator, drugs are evidence of volition and a possibility of exercising freedom. Nevatia sees his addiction and depressive disorder as analogous, employing similar metaphors

of being trapped and enveloped by darkness. As he writes, “My incarceration seems like an exile, and since exile is by its very nature, sentimental, I grow nostalgic about a home I am convinced I will never return to” (Nevatia 23). His memoir is inspired by his conversations with a fellow addict who has been using cannabis for self-medication and has also written a memoir. The memoir’s focus is the entire process of the growth of its central character that reveals the mutability of mental illness, and challenges the idea of normative embodiment. By describing a difficult period of his life, the narrator writes how that phase was instrumental in shaping his personality and worldviews. He could empathize with the community of addicts at Starlight. The circular hall of the wellness center and the concentric circles within it which admitted and incarcerated the mentally ill resembled Dante’s *Inferno*. His incarceration at Starlight makes him lose all his contacts with the outside world. The inmates are made to engage in various activities to de-addict themselves like engaging in a play, singing, writing poetry, etc. During his stay at the rehabilitation center, the narrator jots down every event of his life in his journals. After his parents arrive at the center, he is released under the pretext that his mental illness will be better handled at home. In the section, “Free Love and Other Stories,” the narrator catalogs his journey at the Falmouth College of Arts following a break-up with his partner back in India and the subtle racism he experiences at the college hostel in Falmouth. He impersonates his counselor’s- Dr. Jane Allsopp– identity in an online chatting portal to continue his conversations with Mallika - his ex-partner. He is told that Shreevatsa, according to Mallika, is given to borderline personality issues and a schizophrenic temperament. These episodes trigger his mental health. As the narrator writes:

Bipolarity, I understood somewhat belatedly, does not commence with your diagnosis. Mania, in fact, only pronounces a predisposition that your acts and thoughts had indicated since you were a child. (Nevatia 46)



Nevatia emphasizes on the temporal aspects of bipolar disorder that the condition is not merely a diagnosis at a specific point in time but rather a complex interplay of behaviours and predispositions that may have roots extending back to childhood. Nevatia distinguishes his self and his mind as separate entities. During his manic phase, he develops a fascination for Lord Shiva and wants to mirror his form; he smears the cigarette ashes on his forehead when the voices in his head grow increasingly restless. During this phase he is unable to suppress his desires. In those moments, alcohol tends to conceal his mental instability (Nevatia 50). In strange ways, his use of drugs and alcohol becomes a form of “self-medication” in response to his bipolar condition. Nevatia nostalgically describes his addiction habits where his drug problem seems to be less of a problem than his bipolarity. He devotes a section of his memoir to describe his philandering days in the throes of addiction and illness—he describes his bond with Urvashi, who was still unaware of his manic spells of depression. He uses cinematic metaphors to describe the periods of his intimacy with Urvashi which made him feel that he was free of language. It interrupts his spells of mania. The period of his discreet and “No Strings Attached” intimacies with women who are merely “substitutes for one another” provides momentary relief from his dissociative moods. At the psychiatrist’s chamber, the narrator identifies himself as “Advaita,” meaning a rejection of dualities. He contemplates the co-existence of numerous possibilities and personas within himself (Nevatia 90). In the section “The Invention of Sex”, the narrator describes the period of his adolescence and his sexual abuse at the hands of his cousin. He begins by describing the convoluted world of the manic person when one loses one’s grip over the real. The manic mind conjures up stories replete with “outlandish exaggerations” (Nevatia 92) since the mind has the propensity to travel distances which would not have been possible in sober and mundane moments. He continues to describe the cardinal influences of Ramayana and Mahabharata on his family and the worldviews his parents had instilled in him. Back in his childhood days, he was a plump child

and had to face significant body-image issues because of which he faked illness to avoid participating in school programmes. It is during this time that he is drawn to his cousin- Satyah- who seems to be his protector. The narrator pretends to like Satyah's interests and they indulge in sexual transgressions. These transgressions are pleasurable to the young narrator and his teenage self is unaware of the magnitude of the situation which will have an adverse effect on his moods. As he advanced his adolescent years, he is able to protest against Satyah's advances. During his manic phases, he recalls those moments of his original sin with his cousin and feels that the act of revenge could alone offer justice. In the section "Difficult Loves", the narrator describes the thought of imagining mood oscillations of his oppressor Satyah, which gives him much gratification. He describes the beginning of his relationship with Gauri where he acts as the anxious lover. He often read books, listened to music or watched movies to calm himself and map the progression of his life. He writes:

There is undoubtedly something self-serving about using literature and cinematic narratives to map-somewhat obsessively-the progression of one's life...Mania deludes me into believing my memory is eidetic, while medication and depression can sometimes give rise to an amnesia that seems permanent... (Nevatia 83-84)

Nevatia seems to be exploring the complex interplay between mental health states (mania, depression), medication, and the construction of personal narratives. He stresses on the recognition of the subjectivity and selectivity inherent in crafting one's life story, especially when influenced by the highs and lows of mental health experiences. The narrator hints at the challenges and nuances of memory and self-reflection in the context of mental illness. His bipolarity forces him to engage in emotions that he considers sinful-jealousy, anger, hatred and resentment. His depressive episodes necessitate a transformation since his multiple selves often refused to co-exist. His mood swings, anger and resentment attitude towards people are necessitated by his manic self in that assumes moral superiority. Concerning the breakdown in language's ability to convey meaning in the context of the manic subject, Nevatia observes:

“Linguistic dexterity often gives manic subjects away. Their sentences defy punctuation. It is hard to give a comma to their thoughts, and they certainly do not respect the full stop” (102). In the chapter “I am Shiva”, the narrator describes one of his visits to the Kumbh mela where he finds himself strangely drawn to the figure of Shiva. The hymns sung in praise of the lord or the mangala aarti soothes his senses. He finds in the story of the Shiva linga a thrill that is “delectably dionysiac” (Nevatia 120). He further writes “If bipolarity had to be assigned a God, Shiva would be the obvious choice. Meditating for centuries on end, he finds an oblivion every depressive craves” (Nevatia 121). His association with the mendicant- Lord Shiva, who, too, is frequently associated with cannabis, called bhang in India. The reference to Shiva as a bipolar could be on account of the fact that in Shiva temples, the Lord is usually offered venomous and hallucinogenic flowers and fruits of “dhatura”. As Kal Bhairav, he is offered alcohol. Nevatia might have come across the references to addiction and Lord Shiva through his extensive reading. As he explains further, similar to Shiva who drinks the venom while the gods and demons are churning the ocean for the nectar of immortality, similarly, Nevatia finds his pain and distress difficult to swallow and anger difficult to spit out (Nevatia 122). As for Shiva, bhang obviated the world and removed its indulgences. Likewise, for Nevatia, marijuana caused paranoia and then his senses discover a sharpness. This was the transcendence he was looking for (Nevatia 134). Nevatia acknowledges that there is something “self-serving” about using literature and cinematic narratives to map the progression of one’s life, particularly in the context of his experiences with mania, medication, and depression. This could imply that he recognizes a certain level of subjectivity or self-indulgence in the act of constructing one’s life story through the lens of literature and cinema. Nevatia’s use of the expression “somewhat obsessively” suggests a deep and intense engagement with the act of mapping his life through literary and cinematic references. This could indicate a compulsion or an intense desire to find meaning or coherence in his life story through these cultural narratives. Nevatia notes that

mania deludes him into believing his memory is eidetic or photographic. Mania is often associated with heightened energy, impulsivity, and sometimes a distorted sense of reality. In this context, Nevatia is suggesting that during manic episodes, his perception of memory becomes exaggerated or distorted. On the other hand, Nevatia also describes that medication and depression can give rise to an amnesia that seems permanent. This suggests that the effects of medication and the depressive state may influence memory differently, potentially leading to forgetfulness or a sense of permanent amnesia. Nevatia refers to himself as “Lord Shiva” in a metaphorical or symbolic sense which may serve as a way for Nevatia to express and explore certain aspects of his lived experience with bipolar disorder. In Hindu mythology, Shiva is often depicted as a complex deity with both destructive and creative aspects, representing cycles of creation, preservation, and destruction. This complexity may resonate with the highs and lows, as well as the cyclical nature, of bipolar disorder. Nevatia associates Shiva with meditation and finding an oblivion that some individuals living with depression, crave. Shiva, as a meditative deity, is known for long periods of meditation and detachment from worldly concerns. This could have metaphorical parallels with Nevatia’s search for moments of calm and relief from the challenges of bipolar disorder. After his manic phases are over, Nevatia writes that language becomes malleable. He observes:

I had written my essays in a state of mild euphoria, and over that sleepless week, I was continuously surprised by how malleable language had begun to seem. Words which were once remote miraculously made themselves available. Academic jargon was easy to unpack, and authenticity was mine to claim. Without the structure of formal assignments, however, my thoughts grew unruly, racing from one suggestion to the next.

(Nevatia 135)

During his manic phases, the narrator constantly speaks of himself in the third person. For him, the longing for communication and connection is a characteristic of his mania, in contrast of many misconceptions. Speaking in the third person during manic phases reflects a sense of

detachment or disconnection from oneself. This linguistic choice can create a psychological distance, as if the person experiencing mania is observing or narrating their own actions from an external perspective. During his visits to one of his psychiatrists, Nevatia comes up with a view of his manic behaviour with which he finds much resonance.

When you're manic, you're narcissistic, and you expect the world to live up to those moral and social standards you've created, and when you're depressed, you are again racked with fear and guilt because those ideals, you find, are impossible for you and the world. It's a cycle you have to break. (Nevatia 231)

The psychiatrist also tells him that his teenage experiences with his cousin is not abuse but incest involving the consent of both partner which troubles him. He is advised to write a letter to his teenage self (in his head who is still in the throes of trauma) and confess his feelings. Towards the end of his narrative, he forgives Satyah after learning that he has been diagnosed with depression. He defines himself in terms of a centrifugal force as against a centripetal force—suggesting at the impossibility of comprehending or narrativizing the life of a bipolar person. He opines that “The centripetal force moves you to the centre. It is the force that seeks to regulate us and our language. The centrifugal force wants to break away and create a multiplicity. I am that centrifugal force” (Nevatia 256). Nevatia suggests that the centripetal force is associated with moving towards the center and seeking regulation. In the context of Nevatia’s narrative, it may symbolize the pressure to conform to conventional narratives and structures. Nevatia identifies himself as the centrifugal force, which wants to break away and create a multiplicity. This represents a desire for independence, diversity, and the rejection of a singular, centralized narrative. The metaphor of centrifugal force is a way for Nevatia to convey the dynamic, unpredictable, and multifaceted nature of bipolar experiences. It suggests a force that resists easy categorization and embraces diversity in the narrative. Thus, Nevatia’s memoir brings a human perspective to the struggles of individuals dealing with severe mood disorders. These individuals are in a constant battle and dialogue with their “alterities”. The

memoir raises intriguing inquiries regarding the breakdown of language during times of illness, non-normative embodiment, and the experience of living life on the edge. It appears that Nevatia is consistently connecting and disconnecting himself from his ever-changing mental states, which is an effort to exert control and alleviate distress. Through analysis of the selected narratives, it seems that it is through the power of narrativizing one's experience, in which the author is the narrator as well as the critic at the same time, draws out a pattern, using memory and the powers of description. To sum up, therapeutic literary narratives often aim to provide individuals with disabilities and mental illnesses a platform for self-expression and empowerment. However, therapy is not the ultimate aim or motive of all literary narratives nor can therapy always be adequate to describe trauma and illness. The selected narratives are authored by authors who have lived through these experiences, and their stories can help validate the feelings and experiences of those who share similar conditions. Sharing one's story can be a healing process, allowing individuals to process their experiences, emotions, and trauma. Reading these narratives can also be a source of comfort and catharsis for those facing similar challenges. In the works of Shreevatsa Nevatia's *How to Travel Light*, Swadesh Deepak's *I Have Not Seen Mandu*, and Gayathri Prabhu's *If I Had to Tell It Again*, the recurring theme of the inadequacy of language to fully capture the complexities of mental illness resonates deeply. Despite their distinct narratives and voices, these authors grapple with the limitations of language in articulating the nuances of mental health experiences. Through their introspective journeys, they reveal how words often fall short in conveying the depth of emotions, the intricacies of symptoms, and the profound impact of mental illness on one's identity and relationships. This recurrent motif underscores the profound challenge of representing mental illness authentically and urges readers to recognize the inherent complexities and ambiguities inherent in the human psyche. As these authors navigate the labyrinth of their minds, they invite readers to confront the inherent inadequacy of language in

capturing the multifaceted nature of mental health, compelling us to embrace empathy, understanding, and compassion in our engagement with mental illness narratives. The next chapter is an attempt to explore the intricate relationship between the carer and the cared in narrating the experiences of disability and mental illness.



## CHAPTER TWO

**Caregiving and narrative agency in Tito Mukhopadhyay's *Beyond the Silence: My Life, The World and Autism*, Shama Husain's *Psychlinis*, Himanjali Sankar's *Mrs. C Remembers* and Pankaj Varma's *Silver Haze***

Eli Shaw's<sup>17</sup> memoir *If I Die Before I Wake: A Caregiver's Journey* (2023) is a deeply moving memoir that delves into the author's life as a caregiver and his involvement in hospice care for individuals facing terminal illnesses. The book is a poignant exploration of the challenges, emotions, and profound moments that caregivers encounter while tending to the needs of their loved ones. He underscores the real-world problems that affect families worldwide today, touching on the pain and sorrow that accompany the caregiving journey. Along similar lines, in Lisa Genova's *Still Alice*<sup>18</sup> (2013), in addition to her family, Alice also relies on professional caregivers as her condition deteriorates. These caregivers are essential in providing medical and emotional support, and their roles reflect the broader societal aspect of caregiving for individuals with Alzheimer's. Genova explores the ethical dilemmas that caregivers often face, such as the decision to place Alice in a care facility or the family's struggle to balance her

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<sup>17</sup> Eli Shaw's life is marked by a lifelong commitment to caregiving and community involvement. From a young age, he demonstrated a dedication to protecting and assisting individuals with disabilities, including volunteering with youth groups and founding Camp Happyness. He also pursued various professional paths, including work in photography, retail, and theater, and served in roles related to homelessness, substance abuse, and HIV/AIDS education. Eli's extensive experience in different fields, combined with his passion for community service, led him to work as an Educational Technician for schools in Vermont and participate in various boards and non-profit organizations. His current focus is on providing respite care for people with Traumatic Brain Injury (TBI) by restoring a historic Victorian property. Throughout his life, Eli's mission has been to enjoy, learn, and leave a positive impact on the world.

<sup>18</sup> Lisa Genova's *Still Alice* has had a significant impact in raising awareness about Alzheimer's disease and promoting empathy and understanding for those affected by it. The book was later adapted into a successful film starring Julianne Moore, who won an Academy Award for her performance as Alice Howland. Genova's novel and her efforts to shed light on the experiences of those with Alzheimer's have made her an influential figure in the field of medical fiction and neurodegenerative disease awareness.



autonomy with her safety and well-being. These decisions are emotionally fraught and raise questions about the rights and quality of life of individuals with Alzheimer's and the role of caregivers. In the previous chapter, I attempted to explore how literary narratives on disability and mental illness can have therapeutic effects for the narrator in various capacities. The relationship between therapeutic narratives and a caregiver's or care narrative lies in their shared goal of promoting understanding, empathy, and support for individuals with disabilities and mental illnesses. While therapeutic narratives focus on the lived experiences and empowerment of those directly affected, caregiving narratives highlight the often-unseen struggles of those who provide care and support. These narratives complement each other, creating a more comprehensive and compassionate view of the challenges and triumphs associated with disability and mental illness. It is important to recognize that the two types of narratives can coexist and even intersect. For example, a therapeutic narrative might include the perspective of a caregiver, offering a more holistic portrayal of the situation. Ultimately, both types of narratives contribute to a more informed and compassionate society, fostering empathy and a deeper understanding of the complexities surrounding disability and mental illness.

Caregiving narratives primarily focus on the experiences and challenges faced by caregivers of individuals with disabilities and mental illnesses. These narratives highlight the immense dedication, sacrifice, and emotional toll involved in providing care. They serve as sources of support for caregivers. They offer a sense of connection, validating and understanding, as caregivers often share similar experiences and emotions. These narratives can provide support to caregivers by reducing their sense of isolation and equipping them better to handle the challenges associated with their role. Caregiving narratives can also contribute to advocacy efforts by shedding light on the needs and rights of individuals with disabilities and mental illnesses. By sharing their experiences, caregivers can raise awareness about the

challenges they face and the importance of providing better resources and support for both caregivers and care recipients. In this chapter, I argue that the role of the caregiver is central to the disabled and mentally ill protagonist's understanding of their own selves and identity. Furthermore, it is worth considering that care writing can be seen as a form of caregiving in its own right. Following Rebecca Bitenc's lead, I aver that the chosen narratives not only offer insights into caregiving but also have the potential to contribute to the broader exploration and advancement of care writing. Within this chapter, I make an effort to outline how we can develop methods and strategies for providing care based on the study of care writing. Disability and mental illness life-writing and fiction frequently delve into the intricate relationships between individuals with disabilities or mental health conditions and the individuals providing care for them. These relationships can be multifaceted, dynamic, and filled with emotional complexity. Caregivers can be family members, friends, healthcare professionals, or support workers. These narratives shed light on the dynamics, challenges, and love that define these relationships. Literary narratives allow individuals with disabilities and mental illnesses to express their experiences of dependency and independence. Caregivers may provide necessary support, but the desire for autonomy and self-sufficiency is often a central theme. These narratives explore the tension between needing assistance and wanting to lead an independent life. They also raise ethical questions related to caregiving, such as the decision-making process regarding treatment, medication, or end-of-life care. These dilemmas can be thought-provoking and challenge readers to consider the moral aspects of caregiving. Caregiving experiences are not one-sided. Caregivers also undergo personal growth and transformation. Disability and mental illness life-writing and fiction can highlight how caregivers evolve in their roles, gaining new perspectives and insights into the human experience. Their collaborative storytelling, I submit, is a strategy through which the narrative agency is exercised. The role of

caregivers has also been studied “for their capacity to be “relating narratives”<sup>19</sup> that take on the ethical task of chronicling and bearing witness to aspects and events that are inaccessible to the person living with the condition” (Whitehead 63). Caregiving relationships generally involve a person providing support and assistance to a person living with a certain disabling condition. In disability and mental illness narratives, the presence and the role of the caregiver profoundly impacts the person’s understanding of their experiences. What is also important is how the caregiver chooses to represent the story of the person who suffers from a disability or mental illness. It is crucial for the caregiver to approach the story with sensitivity, a sense of empathy and understanding and should refrain from overly controlling and deterministic portrayals of disability. In the texts I propose to study in this chapter namely Tito Mukhopadhyay’s *Beyond the Silence: My Life, The World and Autism* (2000), Shama Husain’s *Psychlinis* (2018), Himanjali Sankar’s *Mrs C Remembers* (2017), and Pankaj Varma’s *Silver Haze* (2014), the caregivers and the protagonists collaborate in narrating their experiences which is a more nuanced representation of the lived experience and which captures the interdependence, complexity and the intricate relationship within the caregiving perspective. Caregiving narratives provide a means for readers to vicariously live through- and think through- difficult issues and complex scenarios.<sup>20</sup> Caregiving in the context of physical and mental disabilities is interesting in the way in which it challenges or problematizes filial ties when the person living with a disabling condition does not feel at-home due to the all-pervasive shame and stigma. In this way, such narratives show how filial relationships are sustained during acts of care rather than how disability and mental illness necessitated care in the first place. The relationship between the caregiver and the person can be situated within a broader framework of which

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<sup>19</sup> See Anne Whitehead’s “Writing with Care: Kazuo Ishiguro’s *Never Let Me Go*”. *Contemporary Literature*, 52 (1), 54-83.

<sup>20</sup> See Rebecca A. Bitenc’s “Care-writing reconsidered: Towards a new practice of dementia care.” In: *Reconsidering Dementia Narratives: Empathy, Identity and Care*. Routledge, 2020.

Harris et.al describe as being “emerging states of illness [and disability] liminality.” (35 emphasis added) So, the idea of care in the select texts is not, as is generally assumed, merely taking responsibility for people who are thought to be in dire need of them. Through the mode of participatory narration by the carer and the disabled person, I argue, promotes empowerment by highlighting and questioning a range of caregiving challenges and choices. These challenges encompass issues like coercion or paternalism in various contexts, including social behaviour, practical aspects of personal care like dressing, feeding, and toileting, the complex decision-making process of when, how, and where to transition someone into institutional care, and considerations related to medical treatment.<sup>21</sup> Although there may be certain overlaps between strategies of providing care to persons with their disabling conditions, the care-decisions discussed in the following chapter restricts itself to or is particularly salient to individuals living with certain cognitive impairments such as dementia, Alzheimer’s disease, autism and schizophrenia. They involve discussing the nature and extent of the disability and the ability to make choices and asserting agency. It also acknowledges the fact we form an important relationship with people and our relationship are constituted that way. In the narratives that I examine in this chapter, the caregivers are either parents or children of a disabled or mentally ill person. The kind of relationship seems to suggest, as Navneet Sethi writes in “The Limits of Caring: Who ‘Cares’ at all?” (2017), “the fundamentals of caregiving involved in any relationship marked by the physicality of the material world as parents are our first caregivers in terms of the dynamics of caring” (Sethi). Defining the idea of care, Sethi writes:

What is the definition of ‘care’? Is ‘care’ related to physical, emotional, social wellbeing of the care receiver? If that is so, is there a criterion or should there be a criterion to decide the eligibility of certain persons for the roles of being parents? If ‘care’ means wellbeing, then the wellbeing of the care receiver requires sincere and unconditional care which can only be provided by persons, who possess the qualities

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<sup>21</sup> See Rebecca A. Bitenc’s “Care-writing reconsidered: Towards a new practice of dementia care.” In: *Reconsidering Dementia Narratives: Empathy, Identity and Care*. Routledge, 2020.

and sincerity and unconditional care. Sincerity and unconditional care are also the qualitative parameters that the care receiver looks for in a care giver. (Sethi)

She recognizes the fact the identities and the personhood of people in need of care is constantly in the process of making or becoming. So “the person in the role of the parent will not constantly be sincere, kind, and unconditional in care because conditions or circumstances or experiences can have a tangible impact on the person that can balance the relationship of care” (Sethi). The aforementioned narratives of caregiving and care-receiving assert selfhood and agency through the medium of their caregiving relationships. Here, physical disability or mental illness merely becomes incidental for the caregiver to narrate the dynamics of family history. The caregiver thus translates the “disabled” subject into someone who is not shorn of selfhood by tracing a family history. This problematizes certain medical narrative of care which, at times, subsumes family history and the aetiology of illness is always put to the forefront. The aforementioned texts, I argue through a collaborative narration not only provide insights into the caregiving predicament but may benefit others who are living with such conditions. They provide empathetic ways of engaging with people without being ‘model’ caregivers. They do not propagate an ideal standard of care practice and thus their narratives become a productive tool for thinking through care practices<sup>22</sup>. The narrators (both the disabled person and the care giver) use techniques such as flashbacks, selective narration, pauses, omissions, metaphors and images, seem to address issues of narrative empathy by heightening the ethical power of disability studies and literary writings. Caregiver narratives often incorporate such narrative techniques to convey the complex and multifaceted experiences of caregivers and the individuals they care for. These techniques serve several purposes such as an aim to connect with readers at an emotional level. Flashbacks and flashforwards can help

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<sup>22</sup> See Rebecca A. Bitenc’s “Care-writing reconsidered: Towards a new practice of dementia care.” In: *Reconsidering Dementia Narratives: Empathy, Identity and Care*. Routledge, 2020.

convey the emotional rollercoaster that caregivers often experience. They allow the reader to understand the past, present, and potential future challenges and triumphs of caregiving. The use of pauses and repetitions mirror the natural rhythms of caregiving conversations. Caregivers often pause to collect their thoughts, and they may need to repeat themselves when communicating with individuals who have cognitive impairments. These techniques can make the narrative feel more authentic and relatable. Narrative techniques like flashbacks and flashforwards can keep the reader engaged by adding a sense of suspense or intrigue. They create a non-linear narrative that can make the story more captivating. Caregiving experiences are multifaceted and can involve a wide range of emotions, challenges, and changes over time. These narrative techniques allow caregivers to convey the depth and complexity of their experiences, showing how their roles evolve and how they adapt to changing circumstances. Caregiver narratives may use these techniques to create symbolic or metaphorical connections between past and present events. For example, a flashback to a childhood memory is used to illustrate how the caregiver's own past experiences have influenced their approach to caregiving. Flashbacks and pauses can be used to provide the caregiver with moments of reflection and insight, allowing them to make sense of their experiences and emotions. These narrative devices can show the personal growth and self-discovery that can occur during the caregiving journey. Narrative techniques in the select caregiver narratives serve to enrich the storytelling, evoke emotions, convey the complexity of caregiving, and connect with readers who may be able to relate to the challenges and rewards of caregiving. By using these techniques, caregivers can provide a more vivid and authentic portrayal of their experiences. In "Moral Obligation, Disordered Care: The Ethics of Caregiving in Margaret Atwood's *Moral Disorder*" (2016), Amelia DeFalco suggests that

One of the central concerns of ethics is what to do with, or about, another person's suffering. What is one's obligation to other people, friends, family, strangers? And what

is one's obligation to oneself? Ethical commitment can prove to be a high-wire act, a struggle to balance distance and presence, evaluation and interaction, abstraction and action, the needs of others and of the self... Questions regarding who should give and receive care and, even more fundamentally, what exactly the giving and receiving of care means are inquiries with both ethical and ontological implications. (DeFalco 4)

The narrators describe the highs and lows, the ups and downs and the complexities that come along with the illness. What stands apart in the caregiving narratives is that they do not attempt to offer quick solutions to the illness but attempt to foreground different phases of the health condition through various shifting points of view of narration. Such collaborative narratives do not attempt to unearth a cure but they dramatize all the intricacies and complexities of care and of living with the disabling condition. The different phases of living with the cognitively impairing condition include diagnosis which involves the initial shock and adjustment to the diagnosis. Caregivers may describe the process of learning about the condition, seeking medical opinions, and coming to terms with the reality of the illness. Caregivers may narrate the stages of treatment, which can include surgeries, medical interventions, therapies, and medications. They may highlight the challenges and uncertainties associated with treatment decisions. The health condition may not remain static. Caregiving narratives often explore how the condition progresses over time. This can include periods of improvement, stability, or deterioration. Caregivers often delve into the daily routines and care practices required to support someone with a health condition. This can involve personal care, medication management, physical therapy, and emotional support. Caregivers may highlight how they try to improve the quality of life for the individual by engaging in activities, adapting the environment, and providing emotional support. Each phase is accompanied by its own set of challenges, emotions, and adaptations. Caregiver narratives often shift between these phases to provide a comprehensive view of the caregiving journey. Suzanne Keen has coined the term “narrative empathy” which is a cognitive and emotional process by which readers engage with

the narrative and become emotionally invested in the experiences and emotions of the characters within a story (40). Quoting Eisenberg, Keen writes, “in readers’ narrative empathy, shared feeling enables a living reader to identify the emotions and sensations of a representation” (Eisenberg in Keen 55). Suzanne Keen argues in favour of a more precise and thorough definition of empathy as ‘vicarious, spontaneous sharing of affect’ (4) in what ‘we feel we believe to be the emotion of others’ (5). But these care narratives neither position themselves as solely sentimental narratives nor attempt to exclusively garner empathy, as there is a potential danger of oversimplification of lived experiences, which may lead to a superficial understanding of empathy. The idea of caregiving is a recurrent theme in the above-mentioned texts and they highlight the complex relationship between the disabled person and his or her caregiver. These narratives delve into the balance between a person with a disability’s need for assistance and their desire for independence. Caregivers may have to navigate this delicate balance, respecting the person’s autonomy while ensuring their well-being. Through a close reading of the select texts, I intend to examine how the idea of caregiving fits into and not only becomes a thematic concern in the work but also a particular style of narration. The idea of caregiving is manifest through the various flashbacks and how the narrators employ their faculties of memory to tell a story of the past in order to highlight the primacy of caregiving. In the texts of Sankar, Varma, Husain, and Mukhopadhyay, family members, whether a child or a parent, find themselves in the position of the primary caregiver who are responsible for providing care. The purpose of caregiving life narratives is to experience the need to work through someone living with a disabling condition. In this chapter, I explore the collaborative role caregivers play in contributing to the disabled person’s coming to an understanding of their own self. I situate the aforementioned narratives of care in a wider context of caregiving life-writing narratives in India. Thomas Couser posits, “genre is not about mere literary form; it’s about force—what a narrative’s purpose is, what impact it seeks to have on the world” (9). In



exploring the role of caregivers and the role they play in life narratives; I attempt to explore the ethical challenges around dementia, autism and schizophrenia care. The most important challenge is to respect the needs and requirements of the care-receiver without compromising their autonomy.

**The transformative power of caregiving narratives: Exploring family dynamics in  
Pankaj Varma's *Silver Haze*.**

Pankaj Varma began his writing career by writing instruction manuals and training materials for his bank but he was not content with his job. Immediately after, he began writing short stories but gradually realized that it was not his genre. He thought of writing his first novel on a topic that was close to his heart- his mother's descent into dementia. Varma was always fascinated by his mother's life story and wanted it to be brought to the forefront. In *Silver Haze* (2014), Pankaj Varma examines the dynamic between his ageing mother with dementia and her primary caregivers, who happen to be the family. He delves into how the central character, Kamala, experiences a significant shift in her relationship with the family over the years, which, in subtle ways, impacts her mental faculties. The tensions within the family circle are considered potential factors contributing to the onset of Alzheimer's disease and dementia in the narrator's mother. In his Foreword to *Silver Haze*, Pankaj Varma writes that his mother was diagnosed with dementia in 2005, and shortly afterwards, her memory began to deteriorate steadily. Varma cites his mother's observation that the dementia person is not completely rendered as a non-person following the onset of the ailment. She writes:

The doctor had told me that my dementia does not mean that I don't remember things. He had explained that the brain acts like a high-fidelity recorder that records every event, every feeling. My ailment only affects the recall and I am usually unable to recall what is recorded in my memory. I don't know how to correct that, but sometimes, once

in a while, something triggers my memory and some event from the past suddenly comes alive for me. (Varma 11)

Further, Varma highlights his mother's desire to narrate her life's journey, beginning from her birth and through the stages leading up to her disease diagnosis. As Navneet Sethi rightly notes, the relationship between parents and children, at the most basic level, embody the fundamentals of caregiving marked by the physicality of the material world. (Sethi) The notion of caregiving is reversed and falls on the children when the parent is ailing or is senile. Sethi further notes that, "if we are to accept the transitionality in the personhood of the parents as caregivers, the reality of change and ambivalence in the attitude of the family and paid nurses or caregivers must also be acknowledged" (Sethi). Similarly in the narratives of Varma, Husain and Sankar, we see the reversal of the dynamic of the caregiving relationship and how the narrators (who is, at times the son or daughter of the cognitively disabled or mentally ill parent) negotiate the terrains of their ageing bodies. In the case of Mukhopadhyay's narrative, for instance, the mother becomes the reservoir of unconditional love and care, in terms of caring and disability. The family becomes the primary site for care in the texts that have been selected for analysis in this chapter, including the management of impairment, since most care is provided within the family and communities and the costs attached to it are comparatively less. Pankaj Varma's ailing mother wishes to recount her life's journey before she loses touch with reality. Much of the events in the mother's life fascinates the narrator and he cannot exactly fathom what exactly led to the decline in her cognitive abilities in her old age. The narrator acknowledges in his foreword to the novel that storytelling was one of the cardinal qualities of his mother. An important aspect of the son's- the primary caregiver's narrative are the stories and folk narratives that forms a part of his childhood memories and the rest are creative liberties taken by the author. The son plays the role of a meticulous observer and a versatile researcher –as he goes through the letters and whatever materials he could lay his hands on from his mother's

past, to narrate the experiences of living with a cognitively disabling condition. The narrator often tries to bring to the fore the voices of some of the other family members and tries to hold up before the reader the processes through which he tries to arrive at the conclusion of a given situation. In doing so, the caregiver narrator creates a relational memoir in documenting his mother's story. Caregivers' life narratives are paradigmatic examples of what Couser, Eakin et. al have termed 'relational autobiographies' (Couser 200). Caregivers or caregiving life-writing describe the shared life history of the carer and the disabled person to an extent that a conventional life-writing does not because the latter may focus more on individual experiences and perspectives, often overlooking the intricate dynamics and challenges inherent in the caregiving relationships. The primary motive as Rebecca Bitenc argues, of a caregiving narrative is that "they are born out of an impulse to memorialize the parent or spouse, as well as out of the need to make sense of the devastating experience of watching a loved person die" (Couser 223). In the prologue, Varma recounts the day when his mother was diagnosed with Alzheimer's disease by the doctor. The doctor suggests the irreversibility of the condition and cautions that the disease is incurable and worsens as it progresses. Following the diagnosis, the narrator's mother is unable to understand how she and her family is going to cope with her illness. She wishes to relieve the burden of her caregivers. The narrator's mother believed that writing her life's journey would "delay the progress of the disease" (Varma 10) and, above all, she wanted to record everything to prevent forgetting. This, his mother believed, would be her first major triumph over dementia. In the novel's epilogue, the son, who is the co-narrator, writes that he has been the mother's primary caregiver ever since his father's passing. The son notes that after the demise of his father, the mother had lost all the faculties of remembering and recalling events, people and things around her, losing her reading and writing abilities, or the ability to comprehend things around her. Varma's narrative depicts numerous journeys of his mother- a transition from health to illness, and her journey as an obedient and dutiful wife

in a strict patriarchal household. The first chapter opens with the mother sitting beside her caregiver at her son's house. As she wanders about in the room, memories of the past come flooding back. She is transported back in Amritsar in the 1950s. She remembers how her father had made it abundantly clear that she has to make the marriage work- no matter how dire the circumstances are. Soon after her marriage, the co-narrator is given a new name- Neeru Sharma, at her in-law's place because apparently her sister-in-law has the same name as she- Kamala. The narrator traces the memories of her childhood back to the 1930s. She describes her years in boarding school, her participation in the student's group to create awareness about newly Independent India. She was an avid reader ever since she was young- she reads every scrap of paper she finds since she is prohibited from entering the drawing room and the kitchen, or even the library and she has to be mostly confined to her room. The narrator writes that her husband- Jatinder had a very sharp memory, who remembers too much in contrast to her who remembers too little, after her diagnosis of Alzheimer's disease. She likely makes this contrast to emphasize the challenges she faces with memory and the contrast with her husband's strong memory, possibly drawing attention to the changes she has experienced due to the progression of Alzheimer's. In one of her diary entries, the narrator's mother first traces the initial signs of mental instability following her husband's ailment. The onset of this ailment attacks her very sense of selfhood. Her personality undergoes massive changes- the modes of communication, her faculties of reasoning and articulation. Her son works hard to merge together the stories and always shows his reliance on the stories of others. The narrator also tries to draw parallels between various kinds of traumatic events and his mother's illness to make sense of her life story. This narrative showcases how the physicality of her cognitive disability puts the narrator's mother in a child-like situation with her primary caregiver-her son. In case of Varma's narrative, the son describes that it is not only the husband's deteriorating health that leads to the decline in his mother's mental faculties. Her dementia is attributed to her

upbringing in a patriarchal family during the 1940s, where women's voices were systematically silenced. Furthermore, following her marriage to Jatinder, her choices were consistently undervalued and unrecognized. Although her husband loses the ability to move solely by himself, his mental faculties remain intact. Unlike her husband, the narrator's mother's inability to remember things takes a toll on her resulting in the loss of social and verbal skills. Although her husband is well looked after by numerous doctors and caregivers, her illness, which is not as visible as her husband's arthritis, is not given adequate attention. This resulted in the mother feeling neglected and lonely. She begins to loathe herself as a consequence. She further describes the attitudes of the house-help who serves his ailing master at the cost of neglecting her. Her husband's demise deeply impacts her already fragile mind. She writes that "the silver haze had become a dark fog now" (Varma 229). Caring, in the context of Varma's narrative, is not taking things at face value but, as the son was, performing the task of interrogation and verification. Caregiving thus becomes a mode of interpreting his mother's narrative and bringing to the fore, the underlying socio-cultural causes that prompt her illness. Through this interpretive act, the narrator tries to be an active respondent instead of being a passive recipient. The caregiver's interpretive act instantiates the reader's responsibility of listening and participating in the narrative and understanding what constitutes care. In the epilogue of the novel, the narrator affirms that his mother accepts her condition and makes the most of every moment.

...It was a few years later that she learnt to accept her condition. We are all pleased to see her in a state of eternal bliss. She does not remember anything from the immediate past and is exploring life like a child every moment she is awake. Every moment is an adventure for her. (Varma 248)

Varma's narrative has a strong emotional impact that offers readers valuable insights into the ethical dilemmas of dementia care. Additionally, the collaborative storytelling in Varma's narrative delves into the intricate issues of patient autonomy in dementia care. The next section on Himanjali Sankar's novel describes the various complexities involved in caregiving in the family.

**Narrating the complexities of caregiver narratives: Writing, suffering, and ethics in  
Himanjali Sankar's *Mrs C. Remembers*.**

Himanjali Sankar is an Indian novelist and teaches English Literature to undergraduate students. Her two most important works include *Talking of Muskaan* (2014) and *Mrs C Remembers* (2017) which deal with issues that are not the major themes of other novelists—interpersonal relationships and dementia care. The caregiver's writing besides attempting to memorialize a person living with a disabling condition, also delves into the therapeutic qualities of writing one's story which has been discussed at length in the first chapter. Like Pankaj Varma's *Silver Haze*, in *Mrs. C Remembers*, writing serves as both a coping mechanism and an emotional outlet for dealing with the challenges that arise during the caregiving process. In this connection, Thomas Couser writes that writing can be 'a way of grieving, of achieving – or at least approaching – emotional closure on a painful chapter of one's own life' (228). As Renu Addlakha rightly observes in her article "Kinship Destabilized! Disability and the Micropolitics of Care in Urban India (2019)" that "disability is often lived as a family experience" (28). The life narratives of Mukhopadhyay, Husain, Sankar and Varma make it evident that interpersonal relationships and intrahousehold dynamics play a crucial role around caregiving and coming to an understanding of one's self in relation to the family and one's disabling condition. What constitutes the social force of narratives of dementia or similar

disability caregiving narratives is their ability to draw public attention about the ethics of care. Narrative accounts of Pankaj Varma, Tito Mukhopadhyay, Shama Husain and Himanjali Sankar not only challenge the stigma attached to a particular disabling condition, but attempt to create awareness about the financial, practical, emotional, and ethical problems attendant on this condition.<sup>23</sup> In Himanjali Sankar's *Mrs. C Remembers* (2017), the caregiver's account tries to restore agency and selfhood to the protagonist who is diagnosed with dementia and Alzheimer's- in this case, the caregiver's mother- Mrs. Anita Chatterjee or the eponymous Mrs C. Ann Burack- Weiss, in her study of caregiving memoirs draws parallels with narratives of holocaust, slavery or the great depression. She focuses on the various social, political and historical factors that might have led to the various experiences of suffering. Burack-Weiss identifies the "fable" of the caregiver's journey, which serves as a shared narrative representing the collective understanding of providing care to someone in distress. This collective narrative does not necessarily aim to uncover "what really happened" but, instead, serves as a means of how experiences are comprehended, structured, and communicated by writers and readers who are immersed in caregiving situations. (Weiss 121). Sankar's novel identifies the causes of her mother's cognitive disability as rooted in the family. There are two narrative voices in the novel- Mrs. Anita Chatterjee or the eponymous Mrs. C and her daughter, Sohini. Besides describing interpersonal relationships of the Chatterjee family, Sankar also describes the effects of dementia and ageing on her mother. The first section, "Mrs. Chatterjee" describes her difficult relationship with her mother-in-law who, in the days after her marriage, berated Mrs C, for her refusal to adhere to certain restrictions. She further describes the thirty-eight years of abuse and insult she endured at the hands of her domineering mother-in-law. The differences between the narrator and her mother-in-law starts to surface when the former refuses to adhere

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<sup>23</sup> See Rebecca Bitenc's "Relational identity in (filial) caregivers' memoirs" (130) in *Reconsidering Dementia Narratives: Empathy, Identity and Care*

to certain restrictions at her in-law's house. The narration alternates between the mother and the daughter. Sohini- the daughter of the eponymous protagonist narrates that, with the death of her grandfather, his wife mellows down a little as she grows frail and senile, and depends on her daughter-in-law- Mrs C, who becomes her primary caregiver- until the family appoints a few nurses- professional caregivers to alleviate the burden of the caregivers within the family. The narrator also describes the grotesque physical appearance of the senile and ageing mother-in-law - "her skin hanging in wrinkled folds from her face and arms, her matchstick legs and fat upper body" (Sankar 12). The image of the mother-in-law as an authoritative, foul-mouthed woman continues to haunt her even in her dreams. Later, the co-narrator- Mrs C, also realizes that her over-sensationalization of her mother-in-law as a grotesque woman evoking macabre images is on account of her consuming news about the recent political riots that had erupted in the country, as she tries to associate everything that is negative and bizarre to her mother-in-law. The deteriorating condition of the Mrs C's mother-in-law only makes her all the more hostile towards the former. But her mother-in-law's ailing condition and senility compels Mrs C to forgive her. In Sankar's novel, the caregiving dynamic between the members of the family highlight the concept of dependency and it also points to a range of power dynamics that operate within the carer-cared relationship. Although the relationship that Mrs.C shares with her mother-in-law is fraught with tensions, nonetheless, she takes up the role of the caregiver despite the onset of her cognitive disability which necessitates the need of care. Despite the tension in Mrs. C's relationship with her mother-in-law, she assumes the caregiving role. This decision highlights a complex power dynamic where the caregiver, despite historical tensions, holds significant influence and control over the well-being of the cared-for individual. It is through the changing dynamics of the caregiving relationship from Mrs C to her daughter- Sohini, Sankar describes the evolution of the mother-daughter relationship in terms of how they attempt to understand each other. So, in the context of Sankar's narrative, the act of



caregiving- the dementing mother acting as the primary caregiver to her senile mother-in-law or Sohini caring for her mother, is not limited during the period of illness or disability (as the bulk of professional “family caregiving” literature suggests) as Burack Weiss correctly notes in “The Caregiver’s Tale: Loss and Renewal in Memoirs of Family Life” (2006), but is an integral, ongoing part of family life (xvii). These role reversals add depth and complexity to the evolving nature of caregiving relationships within the context of the family. The narrative then shifts to Sohini’s perspective, offering insights into her views on her mother, Mrs. C, and her grandmother. Additionally, it explores Sohini’s relationship with her husband, Omar. Her grandmother’s death finally puts an end to the long tyranny. Even Sohini acknowledges how her in-laws disliked her grandmother for her authoritarian demeanour:

...Not too many people liked her. Her in-laws disliked her with a vengeance- from her grandmother-in-law to the youngest children of that household- their shared hatred of Thamma kept that branch of our family united. (Sankar 21)

Sohini also describes her mother’s recurring dreams of her ruthless mother-in-law’s authoritarian nature as Sohini writes that her mother is always “weird about Thamma. I guess if your life till sixty has been defined by this crazy old bat then you can’t be very sane yourself” (Sankar 21). In the next section, Mrs Chatterjee- the narrator reveals that her mother-in-law’s family is conservative and is rooted in many prejudices – their preference for male children, racism and misogyny. Mrs. C’s daughter, Sohini admits that “Ma was programmed to serve” (Sankar 22). At one point in the novel, Mrs. C acknowledges that for the most part, she submitted to her in-laws’ authority:

Conforming came to me naturally. The rebellions and doubts I had, were subliminal, deep below the surface of life as I knew it, not causing any ripples on the surface. I just knew they were there somewhere. Like a ship that has settled at the bottom of the ocean, old and harmless. (Sankar 24)

The death of Mrs. Chatterjee's mother-in-law somehow leaves a deep psychological impact on her, and she begins to look wrinkled and shriveled and it becomes difficult for any of her family members to accept this sudden transformation. Mrs. Chatterjee's forgetfulness first becomes evident when she struggles to remember her daily tasks, like managing her household and overseeing regular religious ceremonies, while also forgetting her daughter-in-law's name. She writes:

I have always been forgetful but recently it has got worse and I know it makes Sohini anxious, though she doesn't make a song and dance out of it like Malini. Malini has been hinting that there is something wrong with me. I told her it is just that I am getting older. (Sankar 126)

As Mrs. C grows older and more senile, her "memory continues to play tricks on her quite often" (Sankar 126). Sankar's narrative describes the protagonist's facial expressions, physical appearance, gestures which provide access to her current state of mind to an extent that cannot be easily ignored. Sankar's novel is compelling in the sense that it enables the reader to look at the world through the disabling person's perspective as well as through the eyes of the caregiver and the care recipient. Sankar employs a first-person narrative perspective from the viewpoint of the person affected by dementia. This approach aims to emphasize the diverse ways in which the experience of living with a cognitive disability can be described by the protagonist with dementia, who retains some semblance of her voice and agency. In the essay, "Care-writing reconsidered: Towards a new practice of dementia care" (2019), Rebecca Bitenc writes that

Caregivers' memoirs explore the dilemmas involved in caring for someone with progressive cognitive impairment. They hereby provide a means for readers to vicariously live through- and think through- difficult issues and complex scenarios. (161)

Since the primary caregiver lives with the person with cognitive disability, familial caregivers are in a position to identify that person's evolving needs and to advocate for them when the needs are not being met-whether in the community or in the institutional care, as Bitenc writes.

Therefore, these caregivers have the ability to articulate strategies for people living with dementia or Alzheimer's and their care partners, more holistically. Mrs. Chatterjee's lapses of memory are only described in the narrative she recounts with the members of the family. Mrs Chatterjee's daughter-in-law- Malini- first hints at it when she tells the family that there is probably something wrong with her mother-in-law. However, her husband is not able to see the seriousness of the matter at hand and passes it off as minor health issues associated with ageing. The next instance of Mrs. C's failing memory is evident when she forgets her way out of her sister and her brother-in-law's apartment and mistakes the bathroom door with the entrance door. Her daughter, Sohini whose care decisions are salient in the context of caring for a parent, (which involve assessing the extent of the impairment, and the capacity for choice, agency and responsibility in the person who is suffering from the cognitive disability) expresses her concern when her mother develops an aversion for Sohini's daughter, Shazia, which comes as a shock to her. She notes, "Malini has been trying to tell Sudeep and me for some time now that Ma's memory lapses are alarming" (Sankar 131). Mrs. C, who is always calm and caring, suddenly turns stubborn and wilful. Sohini writes that Mrs Chatterjee "suddenly seems older, retreating into her own opaque world, maze-like and confusing" (Sankar 132). At first, the intricate complexities of dementia do not make much sense to her. However, it is interesting to observe that it is only when her mother's dementia sets in that her daughter, Sohini, starts reevaluating her roles as a daughter. Initially, Mrs Chatterjee refuses to accept her alarming lapses of memory and at the doctor's clinic, she fills in the form as Mrs C. because she has probably forgotten her surname which she passes off as her unwillingness to visit a doctor. The daughter realizes her mother's ailment has almost made it impossible and 'progressively difficult' to engage in a sensible conversation. Sohini also notes how her mother does not have the initial charm and vigour of the days prior to her dementia. She writes:

A distorted version of the person remains. The goodness that was Ma is now reduced to tiresome dithering. Much of her is just a mass of petty paranoia. The IQ reduced to next to nothing yet she knows she was not this person before and tries to compensate with senseless comments that attempt to captivate. It is hard to watch. The person who has the backbone of my life even as recently as four or five years back. The dying brain cells have ravaged her. Even when I see her shuffling around now, I see the person that was, I see the woman who did her best for her children and was fiercely protective of them, who lived in her own world yet was practical and impatient and busy. (Sankar 140)

The nature of problems faced by the caregiver- in this case, Sohini, can be varied and complex, due to the progressive nature of the ailment, and therefore the care-decisions also need to be re-envisioned. In this connection, Rebecca Bitenc observes,

Caregivers' memoirs [and fiction] not only provide insight into the caregiver's predicament but may also indirectly benefit others living with or alongside this condition. These texts model empathetic ways of engaging with people with dementia and of resolving certain caregiving dilemmas, without necessarily representing 'model' caregivers. Indeed, the fact that these caregivers frequently fall short of any ideal (or idealized) standard of care makes their accounts a productive tool for thinking through care practices. (162)

According to Bitenc, "the most challenging ethical dilemmas in dementia care, arise out of the conflicting need to respect the person's autonomy while also protecting the person from harm and fulfilling his or her most basic care needs" (163). Sohini describes the impact of dementia on her mother- Mrs.C and the poignant description of the transformation from the vibrant, capable individual to someone dealing with cognitive decline. Sohini conveys the emotional difficulty of witnessing a loved one's deterioration, emphasizing the profound changes in personality and cognitive abilities. Rebecca Bitenc's observation reflects on the broader implications of caregivers' memoirs and fiction in the context of dementia. Bitenc suggests that these narratives not only provide insight into the challenges faced by caregivers but also serve as a valuable tool for understanding and navigating caregiving dilemmas. Caregivers' accounts,

despite falling short of an idealized standard of care, offer a realistic portrayal of the complexities involved in caring for someone with dementia. Sohini's observations and Bitenc's views highlight the emotional and practical challenges faced by caregivers as they navigate the progressive nature of dementia. Sankar's narrative provides a personal, experiential account of the impact on the individual with dementia, while Bitenc's perspective underscores the potential significance of caregiver narratives in fostering empathy and guiding others facing similar caregiving situations. Both Bitenc and Sankar contribute to a nuanced understanding of the multifaceted nature of dementia care and the importance of sharing these experiences to support caregivers and enhance the broader discourse on dementia. In the novel, Sohini remains undecided over when and whether her acts of caregiving- may at times override her mother's wishes. Sohini observes that the patriarchal household and restricted mobility at her mothers' in-laws' place has 'caused' her dementia. Omar, her husband, who is researching on dementia, disagrees with her and explains that, "Every person with dementia won't be reacting in the same way to every stimulus; it will depend on some core qualities the person always possessed. Everyone won't react in the same way... but maybe the reactions are random. There will be a link to who you were but it might be more tenuous than you are thinking" (Sankar 155). Both of them agree over the fact that age is a possible risk factor for developing Alzheimer's disease and women above the age of sixty-five are more vulnerable than men. In a particular incident, Mrs. Chatterjee reports a theft of her money, which Omar dismisses as a typical symptom of paranoia in dementia patients. Sohini, on the other hand, believes that her mother had always been fearful of the challenges that come with old age, such as physical frailty, mental decline, and dependence. In another part of the story, Sohini describes her mother's cognitive decline over the years, noting that while her mental faculties have diminished, her fundamental awareness of people and things has remained unchanged. Her basic framework continues to stay intact, as Sohini notes (Sankar 146). Shortly after, her mother loses her speaking ability

and only “untethered words” remain (Sankar 156). With the gradual deterioration in her mother’s cognitive abilities, Sohini feels drawn towards her aunt who seems to have her mother’s voice. Sohini observes a discernible pattern in her mother’s illness as she writes:

It is a well-charted linear path along which Ma’s mind walks. The ruthlessness with which her brain cells are dying is not random; there is a pattern to it. There is always a pattern to destruction and even while we see the grid, we are dumbstruck before it. A systematic, progressive meaninglessness which is difficult to counter. (Sankar 159)

Despite recognizing the pattern, Sohini implies that the impact on the individual and the emotional toll on the caregiver are profound. It underscores the challenging nature of providing care for someone with dementia, as the decline follows a systematic course that can be emotionally overwhelming for both the person with dementia and their loved ones. Being married into a conservative family, her mother is regimented to live a life of discipline. She literally had to suppress all her anger, frustration and feelings of disgust and hatred. These feelings return with a vengeance with the onset of dementia. Although Sohini’s husband is dubious of her understanding of Mrs. C’s illness, Sohini strongly believes that there must be some pattern to her changed behaviour and that these are symptomatic variations among people living with dementia. She fears the possibility that her mother may not recognize any members of the family. Memories of her bygone years come rushing to the extent of obliterating memories of the present in Mrs. Chatterjee’s mind. The novel ends with Mrs Chatterjee and her daughter visiting her ailing husband at the hospital and the narrator’s mother reiterating that she has some plans to execute. In Sankar’s novel, the focus is on the intersection of Mrs. C’s cognitive disability vis-à-vis the family. The novel stresses on the various relationship circuits that are centered around the eponymous Mrs.C. Like Pankaj Varma’s *Silver Haze*, the fraught relationships in the family are equated with the changes that come over the protagonist after the diagnosis of her illness is explored in Sankar’s *Mrs C Remembers*.

In conclusion, Himanjali Sankar's novel, *Mrs. C Remembers* intricately weaves together the complex dynamics of caregiving within the context of dementia, shedding light on the transformative journey of both the caregiver and the individual facing cognitive decline. Through the alternating narratives of Mrs. C and her daughter Sohini, the novel delves into the familial intricacies that shape the caregiving experience. Sankar skillfully captures the emotional toll on the caregiver, the evolving nature of relationships, and the profound impact of dementia on the individual's identity. The narrative not only challenges societal stigmas surrounding cognitive disabilities but also serves as a powerful medium to advocate for awareness about the multifaceted challenges – financial, practical, emotional, and ethical – inherent in caregiving. By exploring the intersection of personal and collective narratives, Sankar contributes to a broader discourse on the ethics of care, emphasizing the therapeutic qualities of storytelling and the need for a compassionate understanding of dementia within the familial and societal framework.

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### **Shattered symphonies: Navigating mental illness, caregiving and transformation in**

#### **Shama Husain's *Psychlinis***

Shama Husain is an aspiring writer whose first novel *Psychlinis* (2018) traces a person's struggle with and fight against a serious mental illness known as manic depression or bipolar disorder. It foregrounds how a person who is shorn of all agency and voice, embarks on a journey of perseverance and persistence. Husain's lyrical language and occasional poetry interspersed between the narrative explores the different ways in which the caregiving relationship is negotiated. Like Sankar and Varma, Husain's novel describes the dilemma faced by the caregiver while tending to a parent with bipolar disorder. All the narratives discussed in this chapter situate the dilemmas of caregiving in the context of a particular social, cultural and

familial configuration. As Rebecca Bitenc notes, “the caregiving narrative immerses the reader in the specifics of each case and can, in Rosenblatt’s terms, ‘live through’ the caregiving experience in an aesthetically mediated form” (Bitenc 146). She notes that, “by making use of the affordances of particular media (be it the audiovisual in film, the visual in graphic memoir or the many possibilities of the written word), caregivers’ narratives structure the dilemmas [and the fraught relationship between caregiver and care-receiver] for their readers and signpost pathways towards acknowledging- and perhaps solving – difficult ethical issues in caregiving” (Bitenc 174). In the case of Husain’s novel, the caregiver- care-receiver relationship is between the mother and the son. In Husain’s novel, following the lead of Rebecca Bitenc, I try to examine the caregiver and care-receiver relationship in terms of a relational identity. Caregiving narratives provide a more nuanced understanding of the intricacies of living with a mental disorder. In the author’s preface, Husain writes that *Psychlinis* traces the story of Sara Ibrahim- a woman who has just turned sixty and has been living for the most of her life with bipolar disorder. The protagonist tells her life story through the writings of her elder son- Azad, her own prose and fragments of hers and others’ poetry, and through the letters she writes to her children. The narrator describes her childhood alternating between Aligarh and Delhi. In the initial sections of the novel, the narrator describes the trauma she endures as a child during her visit to a fair which leaves a lasting impression on her mind. The narrative alternates between the past and the present and the narrator is questioned by the doctor who is trying to look for clues and patterns from her childhood. The narrator shares stories from her childhood with her daughter. Most of the narrator’s life is narrated by Azad- her elder son. Azad tries to understand his mother’s illness by reading psychological theories handed down to him by his mother. The narrative voice shifts from the narration of the mother to the son- Azad Ansari who sits on a small wooden jetty which is tethered to a small boat which, according to the narrator, symbolizes freedom which is not granted to his mother because she is married into an orthodox



patriarchal family. The narrator describes the progression of his mother from a timid and shy woman to a more self-willed and a resolute woman. As he sits and ponders over various events that have transpired earlier, he is unsure about what he is going to write- as he finds it difficult to find an appropriate starting point to narrate his mother's story. The memories of the mother's past narrated to him by his mother seem very real to him because of the very picturesque and vivid descriptions of his mother. Azad begins by describing his mother's childhood. His mother- Sara Ibrahim is born in free India and it is reflected in her personality in terms of her carefree nature as a child. He describes her thus:

... This freedom ran in her veins, never to be compromised and never taken for granted; reiterated in her every action but never yelled out, never even uttered. It was not the abrasive kind of freedom that liberates when it shocks and hurts. It was a rooted freedom that took wing without causing so much a stir. It was an amazing kind of freedom, so solid yet so effervescent, that I often wondered if it was ever really there...

(Husain 42)

The narrator then begins to describe the various changes that come about in his mother's life beginning with her preference and a knack for western music. The different seasons of North India gradually paves the way for larger and more momentous changes in the life of the mother. The narrator begins to understand what constitutes normalcy from a book on Abnormal Psychology that his mother had given him. The onset of his mother's mental health condition resulted from her suppressed thoughts and rage in the overtly patriarchal family in which her voice was forever silenced. Much of what Azad knows about his mother's childhood is narrated to him by Tahera Ibrahim- his grandmother's elder sister, whom he fondly remembers as "Nanphu". Nanphu is a great storyteller and she narrates the story of her sister's childhood to Azad in all its intricate details. She is always worried that might miss out certain details from the story. The narrative voice of Husain's novel alternates between Sara and Azad's narration. Since a person living with personality or cognitive disorders such as bipolar disorder, the caregivers or a family member has access to the intimate details of their lives. In Husain's

novel, for instance, Nanphu reveals all the intimate details of her sister's childhood to Azad. Although she seems to violate the privacy of the person with a disabling condition, but these details are important for Azad to know in order to narrate the story of his mother in all its details. Nancy K. Miller, in relation to caregiving writing, picks up on this idea of violation where she writes that authors of such filial caregiver's narratives frequently experience a sense of transgression (16). The writers of the caregiver's narrative- in this case, Azad, grapples with a dilemma between his desire to share his mother's story and the ethical obligation to avoid causing harm to the person with cognitive impairments. This tension becomes especially apparent when the narrative includes breaches of privacy by revealing intimate information that the subject has not explicitly consented to disclose. (Bitenc 130). In Husain's novel, Nanphu and Azad are responsible for violating the privacy of Sara, in bringing her story to the forefront. The novel is narrated by emboxed narrators. In the successive narrative, Sara describes her father- Abba as an authoritarian, a visionary and a listener to Beethoven, Bach, Mozart and Tchaikovsky. The earliest memories that Sara has of her father is the sound of his typewriter which woke everyone up in the morning. Although she remembers her father's physical appearance in all its details, she admits that she did not know him well enough because he was a very busy man. In her father's absence, the narrator closely bonded with her mother. Sara experiences her first triggers and hallucinations, following her father's demise until she is diagnosed with Affective schizoid disorder. She is immediately hospitalized and is treated with electroconvulsive therapy. After her first episode she researches about the ramifications of schizophrenia. This is followed by a period when she falls into a spiral of depression and she describes the physical manifestations of her condition. She writes:

...Despite the depth of despair, despite not having a concept of the next moment, leave alone a tomorrow, in spite of failed coordination so that food in the hand sometimes did not reach the mouth, despite not being able to read or talk, despite not being able to relate to even a single individual, despite the hopelessness that comes when no

emotion can be expressed or even felt, despite so many negative factors too numerous to recall and mention, there was a tiny seed of positive energy inside that even I did not know existed. (Husain 84)

The narrator becomes aware of her disabling condition through the suffering of a fellow student during her Masters, which piques her curiosity. Although she is certain that her mental health condition is triggered by her Abba's untimely death, she does not consider it 'abnormal.' Following a doctor's advice that equates certain periods of heightened ecstasy with euphoria, the narrator begins to ponder her manic episodes, searching for spiritual and religious connections. After her second episode, the narrator is taken to the hospital with her relatives. She vividly recalls the experience and its physical impact on her body:

...There is a lot more that I can remember; feelings, fears, sounds, smells, a cold sweat trickling down my back as I talked to Apia ... things that are now firmly embedded in my memory, but that won't recede to become a memory of memory, things that I can only experience with my mind and in my soul, but I am not, even now, able to translate into words. (Husain 94)

Her manic-depressive episodes occur less frequently after her marriage to Adil. However, after her son Azad's birth, her trigger episodes return in the form of postnatal depression. The narrator also acknowledges the flowering of her creative genius during periods of extended mania.

...Everyone says I was well during these years, and I say that too, as these years were by and large serene, and are peppered with a creative genius of sorts in many areas. Yet, this creativity is cushioned by hypomania, a kind of continuous mania that does not go through the roof, and its lateral thinking can be harnessed to become productive... Flights of fancy became the basis of inspiration and were not some kinds of wild fantasy, whereas delusions of grandeur translated into an assertive confidence. (Husain 109)

The narrator reflects on a period of her life marked by a delicate balance between mental illness and creativity. The protagonist acknowledges that, despite being described as "well" by others

during these years, her mental state is characterized by hypomania. This form of continuous, subdued mania does not aggravate or escalate to extreme levels but, instead, manifests as a source of creative inspiration. The narrator states that the periods of hypomania, serve as a foundation for creativity rather than being dismissed as wild fantasies. Moreover, the narrator frames her delusions of grandeur, often considered symptomatic of certain mental health conditions as contributing to an assertive confidence. Such nuanced portrayals problematize conventional narratives about the relationship between mental illness and creativity, highlighting how the protagonist's unique mental state, characterized by hypomania, channels into a productive and creative force rather than being solely a hindrance. Her son-Azad recounts the diary entries of his grandmother detailing her experiences of living with her mentally ill daughter. Later on, Sara translates these entries into English. Many years later, her son Rumi is also diagnosed as bipolar and in the penultimate chapter of her narrative she acknowledges that bipolar disorder can have a variety of symptoms. The narrator acknowledges that bipolar disorder is a part of herself when she says: "...Yes, I would choose to have bipolar disorder because that is what I have and it makes me who I am. Also, I am more than the sum total of my illness" (Husain 215). Paul J. Eakin discusses "the importance of 'the story of the story' when examining the extent to which a life-narrative represents an appropriation of another's story" (98). He is "primarily concerned with memoirs that claim to incorporate their subject's 'own' autobiography, such as 'as told-to' narratives by former slaves or indigenous people in the US" (99). Although in Husain's novel, the narrative voice alternates between the primary caregiver and the care-receiver, the narrative strategies employed by Husain allows the voice of Sara Ibrahim to shine through. Her narrative is not subsumed under the narrative of her caregiver. Husain's narrative underscores the various ways in which Azad, the narrator, navigates his mother's mental illness and her writings to understand her mental health condition. While the aforementioned narratives occasionally lean towards representing their

disability as a problem requiring a solution, the necessary interventions of both the caregiver and care-receiver's voices raise significant epistemological and ethical questions related to caregiving. These narratives tend to problematize some fundamental assumptions of selfhood, such as sovereign thinking and autonomous reasoning, due to the onset of disabling conditions like schizophrenia, bipolar disorder, depression, and autism, which seem to disrupt one's capacity to recall memories. Nonetheless, there remains a core of reasoning within the persona of the disabled person.

### **Redefining Autism narratives: Agency, relationality and cognitive disability in Tito**

#### **Mukhopadhyay's *Beyond the Silence: My Life, the world and Autism*.**

Tito Rajarshi Mukhopadhyay<sup>24</sup> is a writer and poet from India who is diagnosed with low-functioning autism in his early childhood. The BBC broadcast a documentary called "Tito's Story" and the National Autistic Society published a book called *Beyond the Silence: My Life, the world and Autism* which is a collection of poetry, prose and philosophical texts. His autobiographical narrative, *Beyond the Silence: My Life, the world and Autism* (2000), "investigates the tropes of shame and disgrace that is vital to his encounters of living with a psychologically disabling condition. Two of the important concerns of his narrative are the quest for a specific 'narrative mode' that will sufficiently depict the materiality of his disabling condition and the need to investigate the relations between the brain, the body and the exercise of creativity" (Purkayastha 22). Leni Van Goidsenhoven in her article "'Autie-Biographies':

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<sup>24</sup> The section on Tito Mukhopadhyay's autobiography from this chapter has been published in the form of an article- "Reconsidering Autistic Narrative Agency and the Autobiography: The Curious Case of Tito Mukhopadhyay's *Beyond the Silence: My Life, the world and Autism*" in the *Rupkatha Journal of Interdisciplinary Studies in the Humanities*. Vol 12, No 6, December 2020, 1-13 in the Special Issue on Health Humanities edited by Dr. Sathyaraj Venkatesan, Professor of English, National Institute of Technology, Tiruchirappalli, Tamil Nadu, India.

Life Writing Genres and Strategies from an Autistic Perspective” (2017) uses the polysemous term ‘autie-biographies’ to describe a hybrid mode of life writing by autistic individuals (12). These ‘autie-biographies’ aim to challenge the common belief that life narratives rely on a stable sense of self and are inherently reliable, in order to establish their trustworthiness. Mukhopadhyay’s autobiography, on the other hand, highlights the narrator’s fragmented narrative, depersonalization, lack of completeness, and logical inconsistencies. Mukhopadhyay’s narrative poses some of the fundamental questions on narrative autonomy and autism care. Apart from highlighting the concerns of the care-receiver, Mukhopadhyay’s autobiography also raises questions about the position of the familial caregiver. A significant section of Mukhopadhyay’s autobiography is devoted to describing the various social responses to his disability like the narratives of Sankar, Varma, and Husain. Tito Mukhopadhyay uses personal experience to raise questions about social justice and caregiving in questioning certain unilateral assumptions about autism care. In his autobiographical narrative, I submit that “Mukhopadhyay’s brief memory, his evidently disconnected and elliptical portrayals compel one to re-imagine the type of autobiographical narrative as a genre itself” (Purkayastha “Reconsidering Autistic Narrative Agency and the Autobiography”). The growing interest for the issues of impairment and disability has led to a proliferation of life-writing, journals and books which depict the materiality of living with a cognitively disabling condition such as autism. Stuart Murray avers that “the frequently hidden nature of intellectual disability is, potentially, something that even researchers working in the field of disability and cultural studies, or those working in neuro-scientific research, have failed to surmise” (25). Mukhopadhyay’s autobiography highlights the importance of self-advocacy and empowerment for autistic individuals, encouraging them to have a voice in shaping their own lives and advocating for their needs. Through a close reading of Mukhopadhyay’s autobiography, I argue that it promotes the concept of neurodiversity, which highlights the belief that neurological

differences, such as autism, should be acknowledged and valued as a natural aspect of human cognitive variation. In addition to providing opportunities for care, empowerment and empathy, they also spark curiosity about modes of perceiving the world from the lens of an autistic individual. The inclusion of an autistic narrator alongside his mother's narrative voice as the primary caregiver in Mukhopadhyay's autobiography can have several significant implications for the narrative. It is important to approach this narrative choice with sensitivity and awareness, as it can be a powerful tool for storytelling, but it also comes with ethical and artistic considerations. An autistic and unreliable narrator can offer readers a unique perspective and insight into the challenges and strengths of someone on the autism spectrum. It may foster empathy, understanding, create awareness and shape public attitudes about the daily struggles and triumphs faced by autistic individuals. In Mukhopadhyay's autobiography, he emphasizes that individuals with autism spectrum disorders may not respond to emotions in the same way as someone without the condition, who is often referred to as "neurotypical." He also points out that autism can frequently affect a person's ability to grasp implicit social cues, meaning that someone with autism may not easily recognize emotions like sadness through body language or tone of voice. Tito Rajarshi Mukhopadhyay was diagnosed with autism at the age of three. He grew up in Bangalore and Mysore before relocating to the United States with his mother when he was thirteen. By that time, Mukhopadhyay had gained recognition in the autistic community for his dedication to raising awareness and challenging negative stereotypes associated with the condition. His book, *Beyond the Silence: My Life, the World, and Autism* was published when he was twelve. In Mukhopadhyay's narrative, he primarily attributes much of his disability to the absence or deficiency of verbal communication abilities. Ian Hacking in his article "Autistic Autobiography" offers "a phenomenological investigation of autistic writings from an insider's point of view, and he opines that there is no pre-existing language to comprehend autism by alluding to Wolfgang Kohler and Wittgenstein and further maintains

that one can comprehend the autistic without an a priori understanding of the condition. By citing instances of Temple Grandin and Tito Mukhopadhyay, Hacking offers that their life-narratives are not mere matter-of-fact observations but a learning [visceral and sensory] process which do not really follow the methods by which [neurodiverse] people come to acquire speech” (Kohler and Wittgenstein quoted in Hacking 5). In her book *Autism in a Decentered World*, (2016) Alex Wexler presents an alternative way of understanding autism, one that does not exclusively focus on the physical aspects of autism spectrum disorders. She draws a connection to the Enlightenment era, which established a rigid hierarchy between the mind and body, as well as other knowledge systems that distinguish between what is considered normal and abnormal. In making her argument, Wexler refers to various discussions carried out by philosophers, scientists, and neuropsychologists. They propose that the self in individuals with autism is not only confined to specific areas of the brain without a centralized self-awareness but is also shaped by personal experiences of those living with autism and the perspectives of the scientists themselves. (Wexler quoted in Purkayastha 11-12). In her article “Autist/Biography” (2020), Alyssa Hillary argues that “it is necessary to go past commonsensical understandings of autism and necessitates approaching autism as a theory of the mind. One need not trace or follow a pattern in these narratives for similar symptoms, for they celebrate fluidity of their existence with autism are not symptom specific as per a neurotypical standard” (Hillary quoted in Purkayastha 11). In “Autism as Metaphor: narrative and counter-narrative” (2008), Alicia Broderick and Ari Ne’eman highlight “the disruptive nature of metaphors and symbols in autism narratives, challenging the prevailing neurological understanding of the condition. They argue that the idea of portraying autism as a disease comes from the neurotypical community, which overlooks the subversive potential embedded in these narratives. The author suggests that these alternative narratives within the neurodiverse community can work to oppose the ideological hegemonies present in the perspectives of



neurotypical individuals” (460-461). In the Foreword to Tito Mukhopadhyay’s autobiography, Lora Wing notes that, prior to Tito’s enrolment at the Centre for Social and Communication Disorders, he exhibited abilities that surpassed the general understanding of cognitive disabilities. It is a commonly held belief that individuals with autism often possess one or more talents that exceed their other capacities, such as exceptional visuo-spatial skills or memory capabilities. Tito, for instance, demonstrated the ability to use complex sentences with long words and engage in philosophical discussions about existence. (1). Tito possesses a remarkable skill: he can communicate using an alphabet board since the age of six. With his mother’s assistance, he would point to letters on a piece of paper to answer questions by spelling out his responses. At a very young age, Mukhopadhyay displayed signs of intellectual aptitude by effectively coordinating numbers, letters, and shapes. His exceptional abilities align with a particular “narrative appeal” that Stuart Murray refers to in his essay on autism narratives (Murray 28). In the initial sections of his autobiographical narrative, *Beyond the Silence: My Life, the world and Autism*, Mukhopadhyay observes that people are regularly offended or embarrassed by his speech, actions and movements and medical practitioners used various terminologies to describe his condition. In his autobiographical narrative, the narrator describes his relationship with his mother by describing an analogy of the hand and its shadow thus:

The hand had made a strange relationship with its shadow, and he fluttered it and spent his hours, contented with the lone company of his shadow. And his worried stopped. He shut away the world and felt secure in the presence of the shadow. If only the world could be a game with the shadow! But the reality was that he was drawing himself away and away into the world of the shadow.

(Mukhopadhyay 5)

It is his mother’s lap, which has the warmth and readiness that makes him socialize, notwithstanding his numerous attempts to withdraw into himself due to constant feelings of disgrace and shame and the narrator notes, “He refused every place and even social gatherings.

Even new roads, the garden and people were frightening. Mother forced him to socialise, by taking him to people's homes, and the situation got worse. The lap of the mother should not be let off. The boy now refused to walk" (Mukhopadhyay 6). Mukhopadhyay attempts to reconstruct a self, following his medical diagnosis. In some cases, Mukhopadhyay describes a sensation of losing his body. In other cases, he portrays himself as a disembodied being. In his autobiography, each section delves into a specific aspect of his psychological journey, starting with his childhood in Mysore and Bangalore and progressing through his adolescence in Los Angeles and Austin, Texas. Tito's autobiographical narrative provides glimpses into his family and his relationship with his grandparents, which is essential for comprehending how, at times, they assist him in coping with the shame, stigma, and disgrace stemming from his condition. He also mentions how reminiscences of living with them aid Tito in constructing a narrative from the fragments of his memory. Tito also describes how his family, strictly conservative as it was, looks with disapproval at his mother for her abiding interest in reading and learning. As he writes, "she was bad, as the family members felt that married women who were mothers should not study, disregarding their children. In a nation where death is venerated, where penance is revered, where ambition is viewed as the key to greed and vice, she was bad" (Mukhopadhyay 7). Similarly, Mukhopadhyay describes his unique relationship with the flight of stairs. From an early age he believed that it will lead to God. Tito recounts an incident at the doctor's chambers where he had pulled his parents towards the flight of stairs, much to the wonder of the people around, leading the doctors to infer that Tito had cerebral palsy. Soon after this diagnosis, he describes his sporadic dream in which he is accompanied by a man, who follows him everywhere. After a point, he erases all these images that formed around him. As Tito's mother notes, at times Tito continuously recites:

People, People all around  
Not a one to watch

I search for a someone  
 But I am a clown to watch! (13)

In his autobiography, Mukhopadhyay writes,

...Instead of thinking of autism as a disease, with apprehensible cause, a determinate diagnosis, and a possible cure, it might be more productive to think of it as a “disease entity,” which, “allows us to move away from the positivist kind of descriptive categories of disease and to think of diseases not as discrete objects but as ranges of bodily differences and reaction. (22)

Mukhopadhyay’s anomalous embodiment enables him to recall things and events by associations. After the passing of Tito’s grandfather, the young Tito would persuasively climb to the bed where the corpse of his deceased grandfather was kept. When he saw the incense sticks being lit around the bed, he thinks they were worshipping the corpse, which led him to believe that the flight of stairs led to God. In another instance, with the aid of the white board and his mother, Tito had the option to write down what he felt and experienced. Mukhopadhyay navigates through his disabling condition after he is diagnosed as an autistic person. Exploring new perspectives on autism through research and self-discovery helped caregivers better adapt to the challenges posed by the changes associated with autism. In Tito Mukhopadhyay’s autobiography, the narrator informs that autism influences his perspective on the world as well as his poetic impulses. The intricate patterns of thought, sensitivity to sensory stimuli, and the often-unconventional ways of expression associated with autism finds a channel in his poetic endeavours. Since he cannot associate synchronous sense encounters, he frequently relies on his ability to hear, which he considers more impressive than his vision (Mukhopadhyay 112). In addition, Tito has partial synaesthesia (184) which makes him associate sounds or feelings as colours (Mukhopadhyay 157). Tito’s divided tactile experience (Mukhopadhyay 212) impedes the possibility of framing a sound comprehension of the world. Most of the time, Tito fears the possibility of losing his body. His body is by all accounts dispersed and uncontrollable. This synesthetic experience influences Tito’s poetic expressions, allowing him to convey

emotions, sounds, and sensations in a more complex and rich manner. The infusion of colour into his sensory world offers him a distinctive palette through which to articulate his experiences and feelings, contributing to the uniqueness of his creative output.

In his autobiography, Tito's mother who is the co-narrator, writes that "[t]he kid would not acknowledge the presence of his body, and envisioned himself to be a soul" (Mukhopadhyay 19). Because of his virtual being, he was losing authority over his body. A feeling of denial was etched to such an extent that he was unable to react to any circumstance the manner in which it should have been done (Mukhopadhyay 22). In his article, "Autism as Culture", Joseph Straus proposes a biocultural model of autism in which he recommends that, autism is to some degree nebulous, comprehensive, and heterogenous. In current biomedical discourses, autism lies along a spectrum, from "low functioning" to "high functioning". Given the ever-increasing number of the autistic people, it may be useful to consider autistic people as an agglomeration, a system of widespread subgroups, and that their identities are overlapping, penetrable and permeable. Such instances are significant in underscoring how individuals on the autism spectrum exercise narrative agency which enable them to envision alternative possibilities of writing one's life (211). The narrator affirms that, Tito's mother is working not only for the welfare of her child but for the entire autistic community. At a particular juncture in autobiography, his mother clicks a picture of her son everything which fascinates him because that snapshot affords him a possibility of seeing himself in a photo of his whole and un-scattered body (Mukhopadhyay 151). Tito constantly alludes to his creative potentials despite the constraints imposed by the brain:

With every new skill I learn, more areas of my brain are exercised, [...] Mother would come home and draw diagrams to show me what my nerves were doing when I struggled with taking down dictated words. On the first few days, she would draw the dendrites and make a chain of them. She would draw them very lightly to show a feeble connection among them. As days passed, she would show a darker connection between

them because they were supposed to be gaining in strength as I practiced. I could imagine the neurons making a pathway in my brain, as I showed more motivation and less resistance. (171)

Despite the constraints imposed by his condition, Tito emphasizes his creative potentials, and his mother actively engages in understanding and nurturing his abilities. The mother's efforts to explain Tito's struggles through diagrams demonstrate a deep commitment to his well-being and development. Tito underscores the importance of a caring and involved caregiver, like his mother, in fostering the growth and potential of individuals facing cognitive challenges. In the narrative, there is a reference to an imaginary conversation between the autistic boy and the psychiatrist, in which, after the psychiatrist diagnoses the boy with having autism, he is seen to further withdraw into himself. The mother also describes the boy's engagement with various cognitive abilities such as solving a jigsaw puzzle and crosswords. Narratives like these can enable productive interaction of voices of the writers in ways that can empower the disabled subject. In his autobiography, autism becomes less a signifier of pathology than a term for his sense of connection or empathy, a term that re-orders the world, dismantling the privilege that attend to the neurotypicals. Tito Mukhopadhyay's autobiographical narrative leaves open several other possibilities of exploring the lived realities of autism. The modes of assuaging distress and expunging trauma through narrative possibilities need not be the potential barometer for analyzing similar accounts of living with autism. Such accounts can empower us to reconsider the role of the autistic individual to be the authors of their own autobiography by not necessarily being the sovereign, autonomous self of all autobiographical accounts. Mukhopadhyay's autobiography enables one to rethink the concept of caregiving, neurodiversity which does not bring in the various shades of human difference into their accounts. The neurological makeup of persons cannot be discerned on the basis of an archived set of symptoms and case studies. Mukhopadhyay exercises narrative agency by de-

pathologizing the affliction and recovering one's lost agency in life-writing, thereby illustrating that autism is not a marker of a lack and an aberrant pathology. So, Tito Mukhopadhyay's narrativization of his experience of living with autism does not, in any way, foreclose other possibilities of imagining one's identity and subjectivity of the person living with autism.

This chapter tried to address the collaborative role that caregivers and the person living with the disabling condition play in order to come to an understanding of the self and the world around them. The aforementioned narratives are indeed valuable resources for developing better care relationships- that is care practices, that fulfil the needs of the caregiver and the care-receiver. The act of 'care-writing' attempts to include others who are outside the realm of the family circle by advocating a voice to the person living with disability and mental illness. By describing the alternative ways of living with the disabling condition, they also seek to question certain care practices. Unlike a quantitative medical journal, social science reports or case studies, the narrativization of lived experience in all its complexity and subtleties in a caregiving life-writing or novel provides a more humane and empathetic response to disability and mental illness. Being imaginative literature, they have an aesthetic and empathetic appeal, and are not merely referential points. These texts indeed reach out to others with the intent of developing, a collective societal framework with which to reach out to people with certain debilitating condition and those that provide their care. As Rebecca Bitenc suggests, these care narratives seem to suggest a panoply of treatment options and flexible care tailored to the needs of the individuals, families and communities. (Bitenc, 288). More importantly, these narratives use the mode of storytelling for their own needs as well as for moral and social effect. To sum up, caregiving narratives that focus on disability and mental illness often explore the intricate relationship between the caregiver and the person they are caring for through embodied narration. These narratives provide a unique lens into the experiences and challenges faced by both the caregiver and the individual living with a disability or mental illness. The next chapter

will be an attempt to examine embodied narration in such narratives delves into the physical and emotional aspects of caregiving. It not only describes the practical care tasks but also delves into the caregiver's emotional and psychological experiences. It highlights the bodily sensations, sacrifices, and intimate moments that are part of the caregiving journey.



### CHAPTER THREE

**Embodiment, subjectivity and self-identity in Jerry Pinto's *Em and the Big Hoom*,**

**Shabri Prasad Singh's *Borderline*, Amandeep Sandhu's *Sepia***

***Leaves*, Anirban Mukherjee's *In a Train to Trivandrum* and Joginder Paul's**

#### *Blind*

As a Deaf person, I came from a beautiful and unique heritage that included a multilayered culture, a visual language, and a wealth of stories.

— Nyle DiMarco<sup>25</sup>, *Deaf Utopia: A Memoir - And a Love Letter to a Way of Life*

Nyle DiMarco's quote from his book, *Deaf Utopia: A Memoir - And a Love Letter to a Way of Life*, can be understood in the context of selfhood, embodiment, and narrative agency as a Deaf person, highlighting the importance of acknowledging and celebrating one's unique heritage and culture. DiMarco takes pride in his Deaf identity, seeing it as an essential part of who he is. His Deaf identity contributes to the understanding of his self, and he views it as a beautiful and unique aspect of himself. Being Deaf is a part of his embodiment, and it shapes his experiences, interactions, and ways of perceiving the world. His embodiment as a Deaf person has led to the development of a visual language, which is a key aspect of Deaf culture. The reference to a "wealth of stories" in DiMarco's quote suggests the power to shape and control

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<sup>25</sup> Nyle DiMarco is known for his advocacy for the deaf community and has used his platform to raise awareness about deaf culture, American Sign Language, and the challenges faced by deaf individuals. He has appeared in various media outlets and has been involved in campaigns and projects aimed at promoting inclusivity and accessibility for the deaf and hard of hearing. Nyle DiMarco's work extends beyond the world of modelling and reality TV, as he is a prominent figure in the deaf community and an advocate for the rights and recognition of deaf individuals.



one's own story and the stories that represent a particular community or culture. By acknowledging the richness of Deaf culture and its stories, DiMarco is asserting his agency in telling his own narrative and contributing to the broader narrative of the Deaf community.

In the previous chapter, I attempted to examine how caregiving fiction and life-writing are indeed valuable resources for developing better care practices that fulfil the need of both the care-giver and the care-receiver. They attempt to problematize current care practices which envision a person living with autism, dementia and schizophrenia has no agency and voice. The narration of lived experience in its complexity through the eyes of the care-receiver and the caregiver provides a more nuanced understanding over other sources of information on caregiving. The objective of this chapter shall be to examine that Jerry Pinto's *Em and the Big Hoom* (2012), Shabri Prasad Singh's *Borderline* (2017), Amandeep Sandhu's *Sepia Leaves* (2006) , Joginder Paul's *Blind* (2016) and Anirban Mukherjee's *In a Train to Trivandrum* (2019) focus on embodied aspects of their disabilities and mental illnesses such as physical symptoms, sensory experiences, stigmatization and discrimination, chronic pain and fatigue, medication and treatment effects and various adaptive strategies which, I argue, sheds a nuanced light on what changes and what remains after the onset of their health conditions. To provide a solid foundation for my discussion, I review how contemporary phenomenology and narrative theory, and particularly the notion of embodied selfhood (Kontos 2005) and embodied communication (Killick and Allan 2001) have been productively employed in disability and mental illness life-writing and fiction. I then proceed to a close-reading of the selected life-writing and fiction on physical disabilities and mental health disorders. In this chapter, I address two facets of the relationship between embodiment and selfhood in the context of mental illness and physical disability. On one hand, I explore how mental illness and disabilities affects embodied experiences, including consciousness, emotions, cognition, and physical control, as

well as its impact on relationships due to symptoms and stigma, which, in turn, affects a person's sense of self. On the other hand, I attempt to problematize the notion that selfhood is entirely lost in blindness, schizophrenia and borderline personality disorder. I emphasize that memories, including procedural memory, may persist even when verbal communication deteriorates.<sup>26</sup> Understanding embodied selfhood and embodied communication has significant implications for disability and mental illness, enabling a more empathetic grasp of the losses and the preservation of a person's identity. Such modes of narrativizing one's life-story can enable us to contemplate new ways of thinking about embodiment, selfhood, autonomy, narration and agency in relation to life-writing and fiction. As already stated in the first chapter, Rita Felski's exploration of "deep intersubjectivity," illuminates the intricate representation of individuals as embedded and embodied agents within their social environments. This lens provides a framework for appreciating the nuanced portrayals of disability and mental illness, emphasizing the interconnectedness of personal experience and broader societal influences. I refer to Felski's concept, my analysis delves into the depiction of mental illness and physical disability in life-writing and fiction, examining their profound effects on embodied experiences and sense of self. In this chapter, I undertake a close examination of how mental illness and disabilities shape embodied experiences, encompassing consciousness, emotions, cognition, and physical control. Moreover, I explore the impact of symptoms and stigma on relationships, which, in turn, can significantly influence an individual's sense of self. However, I challenge the notion that selfhood is entirely lost in conditions such as blindness, schizophrenia, and borderline personality disorder. By highlighting the persistence of memories, including procedural memory, even in the face of deteriorating verbal communication, I aim to problematize conventional understandings of selfhood in these contexts. The role that the body

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<sup>26</sup> See Rebecca Bitenc's "Narrating experiences of dementia: Embodied selves, embodied communication" in *Reconsidering Dementia Narratives: Empathy, Identity and Care*. Routledge, 2020.

plays in disability and mental illness life narratives is not adequately explored in literary research. Bryan S. Turner in his essay “The Turn of the Body” (2012) writes that scientific advances in medicine and genetics, in particular the new reproductive technologies, stem-cell research, cryonics and cloning techniques, have given the human body a problematic social and cultural status. For many bio-gerontologists, ageing, disease, and disability are not immutable facts of the human condition, but contingent and therefore malleable features of human existence (1). The importance of the body can be attributed to these scientific and technological changes, alongside the diverse social movements that had gained momentum in the 1960s and 70s such as the disability rights movement and the women’s rights movement. Since then, the growing interest in body studies has been of fundamental importance to social sciences and humanities research. For instance, in 2009, the American Sociological Association has recognized the ideas of body and embodiment as an area of growth and professional importance. Michel Foucault’s contribution to the historical and sociological approaches to the body cannot be ignored. His research mainly focuses on sexuality, medicine, power, surveillance, madness and discourse. The theory of the government of the body or ‘governmentality’ which explored the various regulatory controls (‘a bio-politics of the population’) on the body in *The History of Sexuality* generated a profound sociological interest in the human body. Critical theories and particularly post-structuralism held the view that the body is not a unified or a monolithic category. In other words, these theories reject the idea that the body is a singular, cohesive entity. Instead, they emphasize the diversity, complexity, and variability of the body, challenging traditional or essentialist views that treat the body as a uniform and stable concept. Poststructuralist perspectives often highlight how social, cultural, and historical factors contribute to shaping our understanding of the body, rejecting fixed and universal definitions. It is rather a discursive space where cultural and political discourses merge and clash. As stated before, recognizing the nature of embodied selfhood in disability

and mental illness has important implications for disability and mental illness studies, as it might lead to a more nuanced and sensitive understanding of what is actually lost and what remains in the disabling condition. Embodiment, in disability and mental illness literary studies has been generally used to argue both for and against the notion that selfhood is lost (David 2004 and Kontos 2004, 2005). Embodiment has been seen as a means to circumvent the equivocal questions of selfhood in disability and mental illness (Millett 2011). In this chapter, I do not attempt to define what embodied selfhood is or how it is constituted or compartmentalize the terms such as selfhood, personhood, self and identity (Millett 2011). Instead, I try to examine the idea of embodied selfhood and embodied narration which can be productively used to engage with the materiality of lived experience of the physically and mentally disabling conditions. Pia C. Kontos develops the notion of embodied selfhood (2003, 2004) to capture the idea that ‘fundamental aspects of selfhood are manifested in the way the body moves and behaves (Kontos 556). However, Kontos does not pay adequate attention to the idea that the brain is a part of the body. She argues against cognitive definitions of selfhood but does not acknowledge the fact that the much of bodily actions is regulated by the brain. She, therefore, argues that the aspects of embodied selfhood are at the risk of being affected by physical disabilities and mental illnesses. Stephen Millet’s proposal to ground an understanding of disability in bio-phenomenology offers a useful alternative to Kontos’ account. Instead of focusing on the embodied aspects of selfhood, he focuses on the experience of living with the disabling conditions over time. The ‘bracketing’ of the question of personhood, Millet suggests, allows us to ‘focus on the idea that there is a being with an inner life confronting us, a being with value simply because he or she has a “life-world”- a constructed meaningful world revealed to him or her through their senses’ (515). In *Body Theology* (1992), James B. Nelson writes that the world responds to us because of our embodied selves, and that we respond to the world through our embodied-ness (42). In the proposed texts of Pinto, Sandhu, Paul,

Mukherjee and Singh- the portrayal of the body and embodied communication is important as it sheds light on the characters' experiences and emotions, especially in situations where conventional verbal communication might be limited or insufficient. These narratives demonstrate how the body can serve as a medium for expressing and understanding complex emotions and experiences, particularly in the context of mental health, disability, and personal struggles. Rosemarie Garland-Thomson views disability as "a culturally fabricated narrative of the body similar to what we understand as the fictions of race and gender" (26). Carolin Ahlvik-Harju in her article "Disturbing bodies- reimagining comforting narratives of embodiment through feminist disability studies" (2016) writes:

The body is highly idealized and objectified in Western societies and the social pressure to shape, regulate, and normalize one's body in order to fit a normative standard is strong. The normative body standard is defined by deeply rooted conceptions of normalcy- the normalcy narrative- and governed by a normalcy structure in culture and society. The normalcy narrative not only shapes our senses of who we are, but also restricts the life of people with deviating bodies, and limits the imaginations of those who think of themselves as keeping up with the normate, that is embodying the ideal.

(Ahlvik-Harju 15)

In this chapter, I try to examine the correlation between embodiment, selfhood, identity and narrative using certain narrative devices such as point of view, perspective and focalization, all of which describe the character's mental or bodily perspectives. J. Hillis Miller, writing about Henry James' fiction, writes that these terms metaphorize or even corporealize narrative (124). Brett Smith and Andrew C. Sparkes not only claim that stories are 'projected from and inscribed into the body' but also that 'the body is a storyteller' (19). Rosemarie Garland-Thomson writes, in this connection, "I would like to suggest that 'shape structures story' is the informing principle of disability identity" (114). Here, Thomson describes how our bodies tell stories. Her founding principle- shape structures story- draws upon an essay by Caroline Walker Bynum about metamorphosis and continuity, about change as identity. Garland-Thomson's

twist on this idea is best captured in her exegesis of Simi Linton's memoir of identity formation after her car accident: "Although her new shape is instantaneous, the new sense of self develops as a process that is simultaneously growth and healing. The recently impaired body pulls along the new sense of self, which resists and struggles as it reforms itself within a new community based on a shared sense of being in and relating to the world." (Bynum quoted in Garland-Thomson 119). The changed body pulls along the inner self, shaping and recreating that self in ways before unimagined.<sup>27</sup> I attempt to argue that corporeality plays an important role in subject formation and consolidation of identity in the selected narratives. It was Gilles Deleuze and Felix Guattari who first developed the idea of a fluid conception of the subject in the entire gamut of psychoanalytical theories. A fluid and rhizomatic<sup>28</sup> conception the subject problematizes ableist assumptions on embodiment which looks at a horizontal structure of the body (Deleuze and Guattari).

Following the lead of Susannah B. Mintz, I maintain that Pinto, Singh, Sandhu and Paul present their physically disabling conditions and the anomaly of their embodied selves as a discursive site. The social model of disability and mental illness gained significant ground in the 1970s that emphasizes the role of society and its structures in creating and perpetuating disability and mental health issues. It stands in contrast to the medical model, which primarily focuses on the individual's impairment or illness as the primary source of disability and mental health challenges. The social model draws attention to institutional, medical and family barriers that seem to conspire to make their impairments socially and psychologically disabling. The social model suggests that disability and mental health are socially constructed concepts, meaning that they are shaped by societal attitudes, norms, and physical environments. In this

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<sup>27</sup> See Elizabeth F. Emens's "Shape Stops Story" in *Dialogue. Narrative*. Vol. 15, No. 1 (Jan., 2007), pp. 124- 132.

<sup>28</sup> See Gilles Deleuze and Felix Guattari's "Introduction: Rhizome" in *A Thousand Plateaus*. (trans. Brian Massumi) University of Minnesota Press, 1987, pp. 3-28.

view, disability and mental health issues are not inherent in individuals but are products of the way society is organized. The model argues that barriers and discrimination, such as inaccessible buildings, negative attitudes, and exclusionary practices, are the main sources of disability and mental health issues. These barriers restrict the full participation and inclusion of individuals with disabilities or mental health conditions in society. British sociologist Brett Smith writes,

...Bodies are partly connected and ‘known’ through narrative- the stories they tell. Indeed, we tell stories about, in, out of, and through our bodies. Likewise, as a resource, stories from outside our bodies endow us with a sense of interior, subjective reality and are integral to efforts to communicate our feelings to others (...) This is a call, in effect, for an embodied rather than a disembodied narrative enquiry. (Smith 395)

In the proposed texts selected for study in this chapter, the plot does not solely focus on the protagonist’s mental and physical disabilities as signs of inefficiency, weakness and incapacity as perceived in the social settings. Tobin Siebers writes in “Disability and the Theory of Complex Embodiment- For Identity Politics in a New Register,” (2016) “Disability creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social or historical” (Siebers 273). Zoe Detsi-Diamanti, Katerina Kitsi-Mitakou, and Effie Yiannopoulou inform in the introduction of *The Future of Flesh: A Cultural Survey of the Body* (2009), “the almost obsessive engagement with the body began almost three decades ago” (2), thus placing the introduction of the body in the realm of theory and criticism since the last decades of the twentieth century. Katerina Tsiokou in “Body Politics and Disability: Negotiating Subjectivity and Embodiment in Disability Poetry” (2017) in alignment with the perspectives of Diamanti, Mitakou and Yiannopoulou assert that the cultural connotations assigned on the body in contemporary thinking, they underlie the emergence in an interdisciplinary context of “bodies that are unstable, fluid, and transformable, involved in

the endless process of becoming” (2). The experience of living with either mental illnesses or physical disabilities is communicated through the act of writing the text. This becomes a mode of self-expression as well as an inscription written by the embodied self. These narratives also seek to establish their corporeal difference as a creative force. The first-person narrator in the aforementioned texts cogently narrativize their lived experiences with different forms of disabilities; in trying to rationalize their pain and stigma they attempt to create a dialogue with their ‘other’. In doing so, they consciously experiment with the form of the life-writing and fiction. These texts seem to ask how the stories we tell about mental illnesses and physical disability, both reflect and re- envision our understandings of these embodied experiences. Alice Hall, taking Susan Striker’s cue, in the concluding chapter of her book “Disability and Modern Fiction” observes that literary depictions of physical disabilities and mental illnesses suggest new modes of sensory perception, creative experience, critical energy and embodied knowledge (Striker quoted in Hall 128). Anshu Malhotra and Siobhan Lambert Hurley in their Introduction to “Speaking of the Self: Gender, Performance and Autobiography in South Asia” (2015) suggest that ‘performance’ in the context of life narratives refer to the various semantic and conceptual meanings that the texts make for the audience. Life writing is imbricated in the politics of remembering and what is to be memorialized. The self-referentiality of life writing produces “a” story about the self, not “the” story. However, self-referentiality of the text is not merely inherent in the messages it carries but also in the act of congealing/revealing/withholding certain bits of information (112). According to Ema Loja et al. the subjective and inter-subjective experiences of impaired bodies and intersubjective encounters within society are important aspects of disablement and the construction of a disabled identity (190). While narrating stories about living with certain disabilities or mental illnesses, memory plays a crucial role in the development of the narratives and in reconstructing events from the past in order to establish veracity of its events. Memory, in the narratives of



Mukherjee, Singh, Pinto, Sandhu and Paul solidifies connection between the self and the past. Memory plays a crucial role in making sense of the past and their lived experiences for the embodied subject. The aforementioned authors show the body, as a repository of experiences, becomes a site for the inscription of memories. The physicality of the characters is not merely a vessel but an active participant in the construction and preservation of personal narratives. The act of storytelling becomes a means through which characters grapple with their pasts, negotiate their identities, and articulate the significance of their embodied experiences.

**At the crossroads- Embodiment, mental illness and interpersonal relationships in**

**Shabri Prasad Singh's *Borderline*.**

Born and raised in Chandigarh, Shabri Prasad Singh is a novelist and a mental health activist who aims to raise awareness about mental illness. She was diagnosed with borderline personality disorder in 2012. She has been travelling from her very childhood and has lived in the UK, US and currently resides in Delhi. She describes the dark realities of the mental health facilities in India, the vain hopes given by counsellors and psychologists and she talks about breaking the taboos related to mental illness. In her autobiographical novel, Singh describes the major events that transpired in her life after she is diagnosed with borderline personality disorder. As Jacqueline Simon Gunn writes in the "Introduction: The Borderline Personality Personified" that borderline personality disorder is not solely a disorder residing in the brain of the individual. An individual takes up possibilities disclosed to her or him by the cultural or historical environment (1). Rosemarie Garland Thomson had asserted that the body is so important to a narrative that it actually "shapes" the story (114). In *Women and Borderline Personality Disorder* (2001), Janet Wirth-Cauchon underlines "the shifting meanings of the borderline diagnosis" (37): The depictions and definitions of the borderline disorder refer less

to a real underlying mental illness—an identifiable personality disorder—than to changes in psychiatric discourse itself. Further, the borderline category is ambiguous and contradictory, frequently applied to the patient who is socially deviant or marginal. The effect of labelling a patient borderline is to produce a new subject of psychiatry—the unstable inhabitant of the borderland between sanity and madness (Wirth-Cauchon 38). In the Foreword to her autobiographical novel, Singh writes that she began writing her autobiographical narrative at the insistence of her therapist, who believes that writing can provide catharsis for her and can also come to the aid of others living with similar mental health conditions. Encouraged by her counselor and therapist, she invests significant effort into writing her candid account of living with borderline personality disorder. The narrative challenges stereotypes associated with her condition, portraying a positive therapeutic relationship and debunking notions of instability in relationships and untrustworthiness, generally associated to a borderline person. While the narrative delves into intimate aspects of her life, Singh chooses to fictionalize certain events. Her primary aim is to assist people dealing with similar conditions. She outlines the realities of mental health facilities in India from the perspective of someone living with borderline personality disorder. Following her therapist’s advice, she embarks on this cathartic journey, starting by highlighting the creative potentials of a person who is diagnosed with borderline personality disorder. The major defining characteristic of borderline personality disorder today is instability which applies both to the patient’s personality (or behaviour) and to the status of the concept.<sup>29</sup> As Janice Cauwells writes in *Imbroglia: Rising to the Challenges of Borderline Personality Disorder* (1992), the borderline personality disorder “not only causes instability

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<sup>29</sup> The National Institute of Mental Health defines Borderline Personality Disorder as “a serious mental disorder marked by a pattern of ongoing instability in moods, behavior, self-image and functioning” (my emphasis). Web. 25 May 2020. [https://www.nimh.nih.gov/health/topics/borderline-personality-disorder/index.shtml#part\\_145392](https://www.nimh.nih.gov/health/topics/borderline-personality-disorder/index.shtml#part_145392)

but also symbolizes it”<sup>30</sup>. Shabri Prasad Singh’s narrative challenges the dominant “I” in life writing and emphasizes the role of the body in sharing the human experience. She points out that her body often becomes a subject of scrutiny and spectacle due to the ignorance surrounding borderline personality disorder. Her symptoms and actions do not always align with established medical norms, perpetuating one-dimensional cultural stereotypes in Indian society. The narrative begins with her birth on a winter solstice and provides insights into her family and childhood. Singh describes her early years as a troubled child seeking attention and validation. Despite feeling isolated, her deepest sorrows stem from her parents’ troubled marriage and eventual separation. Her close bond with her father contrasts with her mother’s growing relationship with the family doctor, which contributes to her emotional upheaval. Her parents’ separation, her kidnapping, and abduction are seen as potential triggers for her mental illness. She also believes that her genetic predisposition, linked to her paternal uncle and aunt’s mental health issues, further contribute to her emotional struggles, with the primary catalyst being her parents’ separation. The narrator writes:

The death of my parents’ marriage made its way into my subconscious, and brought about dreams and despair. My genetic make-up, from the paternal side of the family, pointed me towards lunacy. (Singh 34)

Hester Perr in her article “Bodies and Psychiatric Medicine: Interpreting Different Geographies of Mental Health” (2005) contends that focusing on the intricate relationship between the body and mind in the daily lives of individuals using psychiatric services underscores the tangible political dimensions of psychiatric medication (180). In addition to her parents’ separation, she acknowledges a history of mental illness within her family. At the onset of her own illness, she also grapples with the exploration of her desires. Her self-confidence is eroded by her self-

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<sup>30</sup> See Janice M. Cauwells’ *Imbroglia. Rising to the Challenges of the Borderline Personality Disorder*. New York: Norton, 1992.

perceived appearance, which adversely impacts her self-esteem. Living with her strict father becomes difficult, a result of his embittered relationship with her mother, which has left him distrusting of all women. While she holds personal spiritual beliefs, she disavows organized religion for its tendency to foster contempt among people. In contrast to her sister, the narrator's strong reliance on her family, especially her father, hinders her ability to lead an independent life in the United States. During her time in the U.S., separated from her family, she forms a connection with Imran Hafez-ud-din, also known as Haff, the manager of a local hotel. However, her mounting mental anxieties begin to unravel her grasp on reality.

...My mind began to trick me; a hidden anxiety kicked in and I let my mind ruin all the good that was happening to me. My emotions got the better of me and I became a slave to my feelings, and lost my grip on reason and logic. (Singh 53)

These are the first episodes of emotional instability which affects her studies and her relationship with the Guyanese man- Imran Hafez-ud-din. Much of the narrator's anxieties and mental anguish begin after her father's sudden demise, the changes in the relationship with Hafez after her pregnancy, her eventual abortion and her inability to rid herself of an obsession with her Guyanese boyfriend despite their break-up and her mother's remarriage and pregnancy. The ups and down in her relationship with Hafez for the second time leads to further deterioration of her mental health. She writes:

...It felt like an impending doom had fallen upon me and I could not escape it; it seemed my end has come. An arresting pain was going through my chest, and my body seemed to be resonating it. I kept telling myself that it was all in my head; that it would all be fine. Even though I knew it was an anxiety attack- I even recognized the symptoms- I was still not prepared for it. It felt like my world was about to end.

(Singh 105)

When her relationship with Gill fails miserably, she withdraws into a spiral of depression. She writes:

The characters I loved painted me blue. In life there is a lesson, that lesson is to forget those who don't want you. Once you are healed, revisit the painting and you will then see no blue, for when you are strong and love yourself the painting will look and feel right, the painting will ask you to look at yourself with strength and carry on painting with mighty hues. (Singh 126)

Shabri Prasad Singh seems to be conveying a message about the importance of letting go of relationships that are not supportive, focusing on self-healing, and eventually finding strength and self-love. She describes an incident when, unable to cope, she resorted to physical harm like slitting her wrists which becomes an emotional release for her (Singh 129). Her mental health further worsens when an aspiring writer and a friend- Ria, depicts the narrator as a lunatic in one of her novels. This takes a serious toll on her mental health and she resorts to self-harm. Following her parents' advice, she decides to attend the psychiatrists' clinic and has regular counseling sessions with her counsellor and advisor- Purnima. After the narrator is diagnosed with borderline personality disorder, her doctor tells her that its causes can be hereditary, traumatic or biological factors (Singh 173). In the course of researching on the causes of her illness, the narrator unearths that her frantic efforts of clinging to her partners- Hafez, Gill or Pink are mere attempts to avoid abandonment since her father's death has created a deep void in her life. The next cause is her unstable relationship with her mother which borders on anger and hatred, her trouble with her self-image, impulsiveness, a recurring feeling of emptiness (Singh 178-80). After discussing the symptoms of her illness with her therapist, the narrator decides to help people who are living with borderline issues. In a series of conversations with a fellow borderline person- Zoha Khan or Sabrina, who shares her experiences of being in an abusive relationship with the narrator. She stresses on how the borderline person sways between two extremes of behaviour:

...We Borderlines are always lying somewhere in-between- in-between love and hate, neurosis and psychosis, being with someone and then wanting to leave, a safe and clean

life while wanting to destroy ourselves, in-between a sea of emotions and then numbness. (Singh 193)

Singh describes the complex and ambivalent nature of the embodied experience of individuals with borderline issues. She emphasizes the constant state of being in-between various extremes- love and hate, neurosis and psychosis- and the conflicting desires to be with someone and to leave alludes to the emotional and interpersonal challenges that individuals with borderline issues may face. The phrase “a safe and clean life while wanting to destroy ourselves” suggests a profound internal struggle, possibly between a desire for stability and self-destructive tendencies. Her use of the expression “a sea of emotions and then numbness” highlights the emotional volatility that emphasizes the constant negotiation between opposing forces and emotional states. In *Borderline*, this embodied narration allows one to delve into the intricate and tumultuous landscape of emotions, relationships, and internal conflicts experienced by individuals grappling with borderline issues. In the novel, the narrator’s self-identity is shaped by her struggles with mental illness and her interactions with the psychiatric system. The embodied nature of her selfhood is explored in the narrative, showing how her mental health conditions impacts her sense of self and how she navigates her own identity within the context of interpersonal relationships. Her sense of self is deeply tied to her efforts to understand and reclaim her identity. In a chapter ‘Incarcerated to Hell’, the narrator describes the difficulties she faces at the mental health institution to which she is admitted, following her manic episodes. Firstly, she encounters patients who are involuntarily placed in rehabilitation, despite the rules which specify that no person shall be admitted without their consent. Apart from lacking some basic amenities of sanitation and hygiene, the narrator eventually gets accustomed to the place. The narrator also mocks at the rehabilitation center which is primarily a money-extracting institution. Their purpose is to keep the inmates for a longer period prescribing them certain medications so that their recovery can be delayed. The narrator also

describes the story of the divergent voices in her head which she calls Roses and Thorns. While Rose refers to the idealistic world she is living in so far- seductive, Thorns refer to the ground realities of the situation which are blunt. In the final section of the book, the narrator learns to accept her own eccentricities of being a borderline. The narrator writes:

...Life, if seen from a different perspective, is beautiful. People suffering from borderline disorders live quite on the edge, but it is a matter of time until they realize that life can be beautiful for them as well. There is no such thing as the normal. We all have our own unique peculiarities. (Singh 236)

In her autobiographical novel, Singh offers an optimistic perspective on life for individuals dealing with borderline disorders. She emphasizes the idea that life can be beautiful even for those living on the edge of emotional and psychological challenges. The expression living “quite on the edge” suggests the precarious nature of their experiences. However, the hopeful note comes with the assertion that it is just a matter of time until they realize that life can also be beautiful for them. This suggests a belief in the potential for positive change and a more optimistic outlook for individuals struggling with borderline issues. Following Leah White’s lead, I suggest that Shabri Prasad Singh’s autobiographical novel is “an act of discursive resistance” (White 5, my emphasis). White borrows this notion of autobiographical resistance from another autobiography specialist, Sidonie Smith, as Smith’s 1993 book *Subjectivity, Identity and the Body* is extensively quoted by White in her article. Smith writes that “autobiographical writing has played and continues to play a role in emancipatory politics. Autobiographical practices become occasions for restaging subjectivity, and autobiographical strategies become occasions for the staging of resistance” (156-157). Resistance is particularly displayed in what she labels “autobiographical manifesto[es],” that is, women’s autobiographical texts that are “purposeful, bold, contentious” (Smith 157). The narrator of Singh’s text firmly believes that as a writer and blogger, she will attempt to dispel the patterns and myths associated with borderline personality disorder. She tries to steer clear the fact that

bodies should not be predisposed to a particular interpretation which labels it as an aberration or a problem and she describes how she is subjected to various prejudices which is due to the social construction of her mental illness. Shabri Prasad Singh's autobiographical novel *Borderline* demonstrates instability across various dimensions, encompassing bodily, emotional, relational, and psychological aspects. Singh portrays emotional volatility as a significant aspect of her experience with borderline personality disorder. She describes intense mood swings, from moments of euphoria and excitement to periods of profound despair and anguish. This emotional instability is evident in her struggles to maintain stable relationships, as well as her internal conflicts and self-doubt. Singh's narrative highlights the precarious nature of Singh's relationships, characterized by frequent ups and downs. Her relationships with her family, particularly her parents, are marked by turmoil, exacerbated by their troubled marriage and eventual separation. Singh's own romantic relationships, such as those with Imran Hafez-ud-din and Gill, are also depicted as unstable, leading to further emotional turmoil and distress. Singh's portrayal suggests that her bodily experiences are intertwined with her emotional and psychological struggles. She describes instances of self-harm, such as slitting her wrists, as a means of emotional release. Additionally, her physical health may be impacted by her mental illness, as indicated by her experiences of anxiety attacks and other symptoms. The narrative delves into Singh's internal struggles and psychological turmoil, including feelings of emptiness, impulsivity, and a recurring sense of despair. Singh grapples with her sense of self and identity, feeling fragmented and uncertain about her place in the world.

**Examining the intersections between blindness, embodiment and self-discovery in**

**Anirban Mukherjee's *In a Train to Trivandrum*.**



Anirban Mukherjee is a writer and an activist of the *Paschimbanga Rajya Pratibandhi Sammilani*, the largest disabled peoples' organisation of West Bengal, and he is also involved with the National Platform for Rights of the Disabled (NPRD), a national level disabled peoples' organization. Mukherjee is a voracious reader and a lover of sports, history and politics. He is also the editor of 'Pratispardhi Barta', a Bengali journal dedicated to disability studies and he contributes to Bengali newspapers and periodicals. *In a Train to Trivandrum (2019)* centers around Amitabha Sengupta, a blind professor, a divorced and isolated individual who sets out on a train journey to attend a conference in Trivandrum and this journey awakens him from a state of lethargy and inertia. The novel begins when Sandipan, a friend of Amitabha calls him and berates the former for leading a solitary life after his separation from his wife-Anwasha. It is almost unacceptable for Sandipan to see his friend, so active in the university days, fall into a state of lethargy. After the separation, Amitabha's wife leads a productive life unlike Amitabha who is unable to focus on his job or social activism. It is Sandipan who constantly reminds Amitabha that he has larger responsibilities for the society and for the work he is doing for the disabled community. But the manifestations of the separation begin to take a heavy toll on Amitabha, affecting his mental health:

He had cut himself off entirely from the university crowd, from his social media connections and even from his books the bulk of which was stored away in his smart phone. What he fell back on was Rabindra Sangeet and sleep...As for his political connections, he had requested them to let him be for some time. He did the same with the disability movement as well. His decision to withdraw entirely from all these commitments had created consternation among the leaders and his fellow-activists.

(Mukherjee 13)

Michela Summa et al. in their article on 'Body Memory' defines body memory as, 'body memory, embraces the totality of our subjective perceptual and behavioural dispositions, as they are mediated by the body. As such, body memory can be phenomenologically addressed

as a form of “operative intentionality” (Fink 1966; Merleau-Ponty 1945): rather than being a re-presenting or presentifying act of recollection (148). Edward Casey considers how the human body has its own ways of remembering: how we remember in and by and through the body (Casey 147). Amitabha has cut himself off from his previous social connections, including the university crowd, social media, books, and even his political and disability activism. His withdrawal from these aspects of his life reflects a significant disconnection from his previous identity and social engagements. This withdrawal can be seen as a physical manifestation of the emotional and psychological toll of the separation. The fact that Amitabha falls back on listening to Rabindra Sangeet and sleep can be seen as a way for him to cope with the emotional pain and disconnection he's experiencing. Listening to music and seeking solace in sleep are bodily actions that provide him with a sense of comfort and familiarity, allowing him to find refuge in his body's memory of these soothing experiences. Amitabha's withdrawal from his previous commitments and the consternation it causes among his colleagues and friends reflect the toll that the separation has taken on his mental and emotional well-being. His body, in a sense, remembers the emotional pain and stress associated with these commitments, and his withdrawal can be interpreted as an attempt to protect himself from further distress. Amitabha's situation aligns with the notion of Michela Summa and Edward Cassey that physical and behavioural dispositions are shaped by emotional experiences, including the separation from his wife. His actions and withdrawal are a response to the emotional and psychological impact of this separation, and they can be understood through the lens of body memory as suggested by Summa and Casey. In the novel, Amitabha receives an email from Thiruvananthapuram University to participate in a seminar on “Literature and the marginalized groups” and he is asked to participate in a panel discussion on disability studies. However, the email fails to move him due to his sheer laziness. Even his parents and Sandipan fail to convince him to participate in the seminar. Amitabha, previously an active voice of dissent participating in multiple protests

at Rani Rashmoni Avenue, is now experiencing a waning interest in everything. His friend, Sandipan, is determined to persuade him to accept the invitation to the seminar. The only thing that troubles Amitabha is that he cannot not bring himself to write a seminar paper. According to him speaking on the topic is a manageable exercise.

He rummaged frantically in his mind to find a particular starting point of his paper but failed to excavate anything as all the resources lay buried under thick layers of dust, the dust of lassitude, the dust of melancholy. He searched frantically in his computer to pick up some fragments of such information but failed to get anything substantive. He felt completely exasperated and left his writing desk in a huff. (Mukherjee 25)

In the lines quoted above, we can see how the concept of embodied memory applies to Amitabha's situation. His mind is described as being in a state of lassitude and melancholy, which are emotional and physical states. These emotions and physical sensations are part of his embodied memory. The dust that covers his resources metaphorically represents the layers of emotional and physical fatigue that have accumulated since his separation. Amitabha's frantic search for information in his mind and on his computer reflects how his embodied memory is hindering his cognitive abilities. His emotional state and the impact of the separation have clouded his ability to access and retrieve information that would be necessary for his writing. This inability to access information is a manifestation of his emotional and physical state affecting his intellectual capabilities. His inability to write is not merely due to a lack of motivation or inspiration; it's a result of his emotional and physical state, which is deeply intertwined with his memories of the separation. On one occasion, the cab driver curiously asks him how he read the newspaper to which Amitabha replied "there is an application on my phone which allows it to provide spoken feedback. Whenever I touch the screen, it says what's under my fingertips. That is how I use the phone and all that is in it" (Mukherjee 26). While pondering over the article which is yet to be written, he remembers a lecture by his professor during his university days which inspires him to write. However, he is unable to make any progress as he

suffers from a writer's block. Meanwhile, one of the members of the disability rights organization for which he has been working, vehemently criticizes him for accepting the invitation to attend the seminar without addressing the demands of the organization for equal rights. The members are disappointed that Amitabha cannot balance his academic duties with his responsibilities to the group effectively. Nevertheless, Amitabha promptly prepares the memorandum for the disability rights group's submission to the chief minister. He desires to visit Trivandrum, not only to attend the seminar but also to rejuvenate himself and escape the bitterness that has affected his life as both an academic and an activist (Mukherjee 46). He is extremely passionate about travelling in trains because "the journeys, in a sense, allowed him to venture into worlds he had not lived in, experiences he never had the opportunity of encountering" (Mukherjee 47). During these train journeys, he gains insight into the prejudices people hold against individuals with visual impairments. Amitabha often faces deception due to his disability, and when his escort backs out of the trip to Trivandrum for a trivial reason, a ticket collector seizes the opportunity to extort money from him and falsely accuses him of rule violations. In Amitabha's case, the ticket collector's actions not only demonstrate the exploitation of his disability but also shed light on the broader issue of discrimination and biases that disabled individuals encounter in society. Amitabha is extremely passionate about train journeys because they allow him to explore new places and experiences that he has not had the opportunity to encounter before. These journeys expose him to different perspectives and situations, which are enlightening and inspiring, pulling him out of his state of lethargy and inactivity. Throughout his journey, Amitabha forms a connection with a fellow traveller, Papiya, who is also visually impaired. The narrator also writes about the plight of the blind person whose lives are full of never-ending hurdles:

...Needless to say, that lack of vision entails a seismic shift in the life of a person because it significantly alters the way he or she comprehends the world. The matter

becomes all the more complicated given that the physical environment has been created in such a way that vision becomes quite integral to adjust to it. (Mukherjee 109)

Mukherjee highlights the problems encountered by visually impaired individuals. The phrase “seismic shift” implies a drastic and fundamental change, emphasizing the transformative impact of the absence of vision. The narrator highlights the complexity of the situation by stating that the physical environment is structured in a way that heavily relies on vision for navigation and understanding. This implies that the world is designed with a visual bias, making it challenging for individuals without sight to adapt easily. The narrator highlights the challenges and complexities associated with the embodied experience of blindness, emphasizing how the absence of vision can reshape not only one’s perception of the world but also their ability to navigate and interact with the environment that is predominantly designed for those with sight. From the perspective of a visually impaired person, Amitabha shares his thoughts on the various social problems and political riots in the country. Against the backdrop of the novel, Kerala is embroiled in tensions due to the ban on women’s entry into the Sabarimala shrine. The protagonist, Amitabha, highlights the futility of such practices and draws parallels with previous upheavals in the country, like the Babri Masjid demolition and controversies surrounding beef consumption. Amitabha’s train journey becomes a catalyst for his awakening, especially through his bond with Papiya, a visually impaired girl from Bangladesh who is travelling in the same train. She helps him break free from the emotional hibernation caused by his separation from his wife, Anwasha. Through his train journeys, Amitabha encounters various physical environments, including different train stations and cities. These experiences enable him to better understand the significance of vision in navigating and comprehending the world. He realizes that many aspects of the environment are visually oriented, making it challenging for blind individuals to adapt. In the novel’s concluding section, the blind professor, Amitabha, is invited to a conference on Blindness and

Technology by the Society for Empowering the Visually Impaired People of Bangladesh, advocating for visually impaired individuals' rights. During his lecture, Amitabha emphasizes how technology has played a crucial role in bridging the gap between India and Bangladesh.

He notes:

...Blind people- of both these countries have been able to outsmart our ever so vigilant border guards as we can easily travel hoodwinking the barbed wires dotting the land and share each other's miseries and, in some cases, they are very remote, I admit fall in love with each other. (Mukherjee 212)

In Anirban Mukherjee's novel, the narrator undergoes a transformation during his journeys, which helps him recover from the tragic separation from his wife. The train journey serves as a significant catalyst for reshaping his perspective, providing him with a renewed outlook on life. It becomes the key element that empowers him to regain agency in the face of illness and disruptive events. During these journeys, Amitabha observes and experiences the societal challenges and biases faced by blind people. This exposure to discrimination, prejudices, and the difficulties of accessing information or assistance helps him empathize with the struggles of visually impaired individuals.

### **Perception and sight: Exploring blindness and self-identity in Joginder Paul's *Blind*.**

Joginder Paul is a prolific Urdu writer who has a number of novels and short stories to his name. His novel was first published in Urdu as *Nadeed* in 1983 and is translated by Sukrita Paul Kumar and Hina Nandrajog into English as *Blind* in 2018. Joginder Paul drew from his time as a teacher in Africa, specifically a blind people's home near Nairobi, to craft this story. He relocated the setting to India and the characters to Indians in the novel. In her notes, 'To See or Not to See,' the translator Sukrita explains that the writer was deeply affected by his experiences during this journey to Nairobi, which ultimately inspired him to write the book.

The cataract-clouded white eyes set against the dark African faces left a profound and existential impression on Paul. He faced a considerable challenge in capturing the essence of blindness in words and trying to empathize with the blind experience. Crafting a story with all blind characters marked a unique and challenging departure from his previous writing experiences.<sup>31</sup> *Blind* is a poignant story that revolves around the experiences of the inmates of a home for the blind. The story explores the challenges and emotions of a blind person as he navigates through life, highlighting the sensory and emotional world that becomes more acute in the absence of sight. The narrative delves into the inner world and perceptions of the protagonist, shedding light on the impact of blindness on his daily life and interactions with others. *Blind* is a character-driven story that delves into the themes of disability, perception, and human connection. Paul's novel explores the theme of blindness- both literal and metaphorical, and delves into the complex layers of human perception and existence. The novel examines the interplay between perception and reality. The story revolves around individuals living who a living with a visual impairment. Through their experiences, Paul raises certain pertinent questions about how individuals perceive the world and the limitations and biases that can cloud their understanding of reality. Apart from dealing with the various literal and social implications of blindness, the novel also delves into the various metaphorical connotations of blindness, referring to the inability to truly see and understand oneself. In the novel, there are certain characters, who have sight but are blind to the emotions, actions and desires of others. It explores the intricacies of human relationships in the home for the blind, the challenges faced by the inmates on an everyday basis. Through his poetic language and lucid writing style, Paul employs vivid imageries to portray the characters experiences and

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<sup>31</sup> See Sukrita Paul Kumar's 'To See or Not to See: Some Thoughts, Some Notes.' In: *Joginder Paul: The Writerly Writer*. Routledge, 2021.

emotions. Written in a non-linear structure, Joginder Paul's narrative style in *Blind* is characterized by its introspective and sensory-rich approach. The story delves deeply into the internal thoughts and emotions of the blind protagonist. It often uses vivid and evocative descriptions to convey the sensory experiences of the character, such as touch, sound, and smell. The narrative style is reflective and explores the protagonist's inner world, allowing readers to empathize with his struggles and experiences. Paul's narrative style in *Blind* also emphasizes the significance of the character's perceptions and how they shape his understanding of the world around him. It focuses on the character's thoughts and feelings, making the reader more aware of the sensory details and emotional nuances that define the blind man's life. The narrative style is evocative and immersive, enabling readers to connect with the protagonist's journey and the challenges he faces as a blind individual. Joginder Paul's *Blind* narrates how the residents of a home for the blind, despite their lack of sight, perceive the world through alternative senses and means. In the opening chapter of the novel, one of the residents- Sharfu writes that each member has their unique perspective on life. For himself, he sees through the various imaginative potentials that he is endowed with. As Mary Douglas suggests, "the physical experience of the body... sustains a particular view of society" because "there is a continual exchange of meanings between the two kinds of bodily experience so that each reinforces the categories of the other" (68). To return to the depiction of the blind characters in Paul's novel, the characters make sense of their surroundings through senses of smell, touch and hearing. Paul describes the metaphorical and philosophical meanings associated with blindness. In Joginder Paul's novel *Blind*, physical blindness serves as a metaphor for societal ignorance or lack of awareness regarding deeper truths, injustices, or underlying realities. It symbolizes not only the inability to see with one's eyes but also the failure to perceive and understand the complexities of life, relationships, and societal issues. By using physical blindness as a literary device, Paul highlights the theme of ignorance or



wilful blindness that pervades the narrative, drawing attention to the need for greater insight, empathy, and understanding in the characters and, by extension, in society as a whole. Sharfu's imaginative potentials within himself is not very dissimilar from the world of sight, and where he has unrestricted freedom and mobility. Sharfu lives a cocooned existence since he is fiercely inhibited because of the prejudiced attitudes of people towards blind individuals. Despite the struggles of living a life devoid of vision, the inmates of the blind home engage in tasks such as making bamboo baskets. The shared camaraderie and connection they share in the home for the blind are the means through which they strive to embrace the challenges of living with visual disability. The narrator Sharfu opines that the life of a lone blind man is full of obstacles which can be overcome when spent in the company of other blind men and they engage in productive pursuits. The narrator describes that a blind man's vision is clouded by curtains of the past and that is why he cannot see anything (Paul 10) which indicates that memory shapes their perception and understanding of reality. Memory serves as a means of connecting with their past and forming a sense of continuity in their lives. The narrator reminisces about his childhood spent with Roni, a fellow resident of the blind home who has recently left. Her departure leaves the narrator's world feeling desolate once more. Her absence makes Sharfu realize his blindness all the more poignantly the first time since he believes that the bonds of the blind are born out of feelings and not faces (Paul 13). Bhola- another resident of the home of the blind believes that the blind dwell in memories of their previous lives which cannot be understood or recognized by the sighted majority. The narrator notes that it is through their father Baba, they are able to perceive the world. It is through Baba they:

sense tidings about our lost and forgotten directions- Baba is our eyes. He who bestows sight to others, how can he himself not be able to see. His gait is so confident that nobody can think of himself as blind. (Paul 20)

The idea expressed by Mary Douglas, which suggests that “the physical experience of the body sustains a particular view of society” and emphasizes the exchange of meanings between bodily experiences and societal categories, can be related to what the narrator says about intersubjective connections between blind people in the sense that both perspectives highlight the interconnectedness between one’s physical experience and their understanding of the world and society. The body and its experiences influence how people categorize and make sense of the world. This aligns with the narrator’s description of Baba, who is blind, but through his confident gait and his ability to sense and convey information, he serves as the “eyes” for the narrator and others. In this context, Baba’s physical experience of blindness does not limit his ability to perceive and understand the world; instead, it reinforces the idea that bodily experiences can be a source of knowledge and meaning. The narrator’s description of Baba illustrates how the exchange of meanings between individuals, in this case, blind individuals, can create a unique form of intersubjective connection. Through Baba’s sensory experiences and the narrator’s reliance on him, a shared understanding of the world is constructed, challenging conventional notions of vision and blindness as the blind individuals in this context rely on their shared bodily experiences to navigate and make sense of the world. The narrator notes that for his father, darkness is the medium of sight (Paul 22). Baba, the owner of the blind home believes that at the blind home, there is a sense of companionship in their realization of life. One of the inmates- Bhola informs him that “...one who is born blind constantly consoles himself by saying- darkness is a reward for my blindness... that darkness itself can light up the dark. If he has to remain blind, let his blindness be a boon...” (Paul 41). Baba considers his blindness as a boon and the idea of the sudden return of his sightedness scares him:

...No, I don’t want to be dead while I am still alive; if I announce the return of my sight, I shall become an outsider within my own home... someone who has come here to hold the open lives of the poor blind in the prison of his sight. The habitat of the blind is possible only in the darkness below the earth... fake though it may be, I’ll go

on giving and receiving love with closed eyes...When blind, I was within myself, but as soon as I got eyes, I have leapt out of myself. I turned my eyes away from the mirror so that I could feel myself within my body...

(Paul 47)

In an interview with the newspaper reporter, Baba opines that “one should think of a man as blind only when his sightlessness begins to trouble him” (Paul 70). He writes that he is subjected to prejudices of the society like any other blind person. He says that “...someone who is responsible for keeping the dreams of others intact has no choice but to risk having sight” (Paul 71). Throughout the novel, Paul’s narrator emphasizes the value of perception and sight not solely in terms of physical vision but also in understanding and empathizing with the hopes and dreams of others, emphasizing the importance of a broader, more profound form of ‘sight.’ He uses ‘sight’ as a symbolic contrast, encompassing physical, moral, intellectual, and value-based vision. Some blind individuals possess a ‘third eye,’ enabling them to sense the world around them, while others are adept craftsmen, often referred to as having ‘eyes on their fingers.’ Their heightened awareness of their condition leads some to fear the idea of gaining external sight. Being free from vision grants them a unique sense of freedom in their interactions, both among themselves and with the world. For instance, a basket weaver among them asserts, “...if my eyes were to see, my fingers would go blind” (Paul 46). When an inmate regains sight, they lose their sense of orientation and fear being expelled from the only sanctuary they trust—the home for the blind. Through its characters and themes, the novel reflects on the nature of reality, the limitations of perception, and various alternative routes of navigating the world in the absence of sight. To sum up, Joginder Paul’s novel stresses that embodiment, selfhood, and memory can take on unique dimensions when viewed through the lens of blindness. It challenges conventional notions of physical appearance and visual perception, highlighting the significance of inner experiences and personal memories in shaping one’s sense of self and understanding of the world. Blindness is presented as a

condition that requires a different mode of embodiment and a deep connection to one's inner world and past experiences.

**Journey through the labyrinth: Schizophrenia, family dynamics, and memory in  
Amandeep Sandhu's *Sepia Leaves*.**

Amandeep Sandhu is a Punjabi writer and journalist who writes fiction, non-fiction, essays, opinion-pieces and reviews. Some of his important works include *Sepia Leaves* (2008), *Roll of Honour* (2012), *Panjab: Journeys Through Fault Lines* (2019) and his important work on mental health- *Bravado to Fear to Abandonment: Mental Health and the COVID-19 Lockdown* (2020). In an interview, Amandeep Sandhu remarks that "Sepia Leaves is a true story. It is called fiction because the time line of the story is not entirely real and I have merged some characters while, in other places, I created more than one character from one person. Yet, the events and the emotional content of the story is absolutely and honestly true" (Sandhu). *Sepia Leaves* is set during the politically charged atmosphere of the Emergency of the 1970s. Apart from narrating the lived experiences of schizophrenia, the novel also describes the role of the caregiver and the socio-cultural factors behind mental health problems in a social unit such as the family. Like the narratives of Pinto, Paul, Mukherjee and Singh, the narrator of Sandhu's novel describes the embodied experience of mental illness and also the difficulty of narrating the experience of mental illness. In the opening chapter, the narrator begins by describing the death of his ailing father who is initially diagnosed with angina, but is later referred to a psychiatrist since he starts rambling anonymous disjunctive sentences which makes little sense to the cardiologist. In the last few months, the narrator's father witnesses steady temperamental changes and disorientation followed by erratic and manic behaviour such as the instance when he runs naked on the streets. The narrator recounts the story of his childhood and his mother's

illness, beginning with the death of his father. The narrator recounts that due to his mother's illness, his father tried to build order in his family throughout his life. The narrator notes that 'nothing was normal in his house' (Sandhu 13). The arrival of Mando, the house-help is expected to assist the narrator's mother. The narrator recounts the frequent and intense arguments between his parents, largely stemming from suspicions that the servant, Mando, was perceived as the lover of her husband by the narrator's mother due to her illness. Subsequently, their relationship starts falling apart. Sandhu's novel is aligned to the larger political events that affect the country for instance, the impact of the Emergency on the personal lives of the people of Rourkela. The narrator describes his mother as a woman who is of two opposing temperaments- calm on the one hand and violent on the other. The narrator is seven when he first hears the word schizophrenia from the doctor's prescription. Unable to find its meaning in the children's dictionaries, the narrator asked his father for its meaning:

Schizophrenia. It was the longest word I had heard until then, longer than 'elephant' or 'dinosaur' and much more difficult to pronounce. I went to look up my illustrated dictionary but it did not have 'schizophrenia' in it. I tried the small dictionary that Baba kept on the bookshelf. That did not have the word in it either. (Sandhu 23)

The narrator's father had also heard it for the first time. The narrator describes the difficulties he faces while trying to comprehend his mother's illness during his childhood. Even the narrator's father struggles to explain the meaning of "Schizophrenia" to him. The narrator writes:

I never knew how Mamman would behave in any given situation. Mamman was two Mammans. Once I entered the kitchen and Mamman was shouting swear words at the top of her voice. When I asked for food, she picked up the daal and poured it down the drain. This was the angry Mamman. When I came home the next day, she made some half-burnt puris and kept piling my plate with them even though I was full. She was very calm, as if she didn't hear my repeated refusal. I threw the puris out of the window. That was the over-loving Mamman. (Sandhu 11)

The narrator notes that Mamman's behaviour is marked by extreme and unpredictable shifts, revealing two distinct personas associated with her mental health. The portrayal of Mamman shouting swear words loudly and "pouring daal down the drain" reflects an instance of intense anger and erratic behavior, suggesting the challenges of living with someone experiencing the symptomatic aspects of schizophrenia. This illustrates how mental illness can manifest in unpredictable and disruptive ways. On the other hand, the narrator describes Mamman as being very calm and repeatedly piling the narrator's plate with "half-burnt puris," despite his refusal. This portrays an altogether different facet of Mamman's experience – one characterized by over-loving tendencies. So, the narrator describes such moments of emotional extremes and a disconnection from reality, reflecting the impact of schizophrenia on Mamman's perception and behaviour. The narrator's mother goes for routine visits to the psychiatrist on Thursdays along with her husband. Although the doctor prescribes medicines for her, the narrator's father believes that the medicines are not helping her in any way. After diagnosing her with schizophrenia, the narrator's mother characterizes her condition as what sets her apart from the others in the crowd. As she proclaims: "The most precious brain in the whole world. My brain is most precious, you are my son- Antimony" (Sandhu 23). The temperamental and behavioural changes in the narrator's mother manifest as she starts writing letters to her sister and father but never posts them. She writes vigorously and scribbles words in letters and keeps muttering random words which the narrator does not understand. The narrator witnesses the changes that comes about in his parents' relationship as he peers through the wedding album of his parents:

I come downstairs and open the album with the gold cover that has their wedding pictures. The black and white pictures have turned sepia, the colour of memory... Another life reveals itself as I turn the pages of the album. A life unknown to me, sepia toned. A new life has its own course and to nurture it, the patterns of the old must be forgotten. In order to generate new life a tree sheds its sepia-coloured leaves.

(Sandhu 33)

The use of the phrase “A new life has its own course and to nurture it, the patterns of the old must be forgotten” suggests a recognition that mental illness can lead to significant disruptions in one’s life. The narrator is acknowledging that in order for his mother to move forward and heal, they must embrace the changes brought about by her illness and let go of past patterns or expectations. The narrator researches for material for his narrative and those unsent letters of his mother and the sepia tinted pictures become potential material that forms a large part of the narrative. Sandhu aims to weave a narrative that reflects the tension between the various fragments used by the narrator to construct the story of his mother. Occasionally, these fragments appear as disjointed, stand-alone versions of their family history, rather than seamlessly integrated elements. The sepia toned pictures reveal an altogether different world to the narrator. The sepia photographs serve as a symbolic representation of memories, nostalgia, and a connection to the past. Sepia-toned photos have a vintage and timeless quality, often evoking a sense of history and sentimentality. They may suggest a longing for the past, the preservation of family history, and the desire to hold onto memories. In the context of the novel, these sepia photographs play a role in conveying the themes of memory, identity, and the passage of time. They could also serve as a visual motif to underscore the emotional and psychological journey of the characters. But the sepia-coloured images must be forgotten in order to generate new memories. Memory plays a significant role in helping the narrator understand his mother’s illness. It serves as a bridge to the past, specifically through the sepia-toned wedding album and the unsent letters, which provide insights into his mother’s mental state and her behavioural changes. The wedding album with its sepia-tinted pictures represents a visual link to the past, a time when his parents’ relationship was presumably different and happier. The unsent letters serve as a form of written memory, capturing her mental state and the shifts in her behaviour. Much of the differences between the narrator’s parents is due to their divergent cultural backgrounds. His mother- Mamman can never really accept her

husband- the narrator's Baba who is always a 'poor relation' to her and had to live with him not by choice but force of habit (Sandhu 33). The narrator's father struggles to accept his wife's temperamental differences. When the narrator inquires about the factors contributing to his mother's current mental health condition, the father informs him that her detachment and indifference had been longstanding traits. He also reveals that her temperamental and behavioural changes became more noticeable after the narrator's birth, but even before their marriage, her brother had noted her 'odd behaviour.' During occasional visits to his mother's room, the narrator observed her displaying unusual behaviour:

Sometimes when Mamman was in the bedroom and the door was shut, I would peer in through the bedroom window next to the guava tree. I would see her clearly, though Mamman never noticed me... Impassive, cold and without a trace of emotion or expression. She sat like that for hours: one, two, three... however many. Sometimes I watched her and went off to play. When I came back, she would still be there in the same position. It was almost meditative... At such times, she looked beautiful like a statue. A stony beauty that frightened me. Her silence numbed me. (Sandhu 38)

After the onset of her schizophrenia, the narrator notices significant changes in her physical appearance. She appears to be detached from her own body. The references to his mother who looked "beautiful like a statue" but with a "stony beauty that frightened" the narrator implies that her physical appearance has changed, and her demeanour has become eerie or unsettling to those who observe her. During his childhood, the narrator disapproved of how the residents near his home in Rourkela referred to his mother as 'pagli.' However, when the narrator described these incidents to his father, his father told him:

Mad is somebody not like us, someone who does not believe in things the same way we do, who is not normal. See, we are all a little different from each other: our faces, our handwriting, our way of walking: But mad is when you are more different than is considered normal... And Mamman is more different. (Sandhu 41)



In the novel, the narrator reconstructs the past in the novel as a means of coping with and making sense of the challenges and traumas that he and his family have faced, particularly related to his mother's mental health. He tries to embrace the changes that have come about in his mother after the onset of schizophrenia. It allows the narrator to better understand the root causes of his family's struggles and his mother's mental illness and preserve memories and family history so that it is not lost over time. He tries to process the trauma and emotional scars left by the events in his family's history which is a form of catharsis and healing for him. As the narrator glances through the sepia tained pages of the album, he wonders why had God not made things normal in his family and the reasons behind his mother's illness and his father's aloofness. The narrator remembers that family violence began when his maternal uncle opposed his sister's marriage to his father. When the narrator's mother is admitted to the asylum, the psychiatrist, Dr. Nanda suggests that the narrator's mother be administered electric shocks because that will bring her back to her senses. The narrator's family is unable to accept his mother's 'special illness' as it will bring stigma and shame to the family. The narrator stumbles upon the pages of the half-written diary of his father from which he deduces that his father also led a troubled life:

My experiments with the truth of life happen to be bitter. My physical experiments with life, in the vein of the saint who wrote them, proved to be futile. My self-discovery leads me to frustration and creates emotional and physical needs... My experiments tire me, trouble me, and I am left at the mercy of medicines. (Sandhu 138)

In the epilogue of his novel, Amandeep Sandhu conveys that the narrator's mother's life has remained somewhat beyond understanding. After years of observing her struggle with mental illness, the narrator gradually comprehends the factors that contribute to schizophrenia. As the narrator types the final pages of his story, his mother, who is suffering from a terminal illness, sits beside him. The narrator attributes this illness to her reliance on medications. He writes:

My mirror from my childhood with a ring of smaller mirrors around it has survived all these years, though it is a little shabby now. When you look into it, it reflects multiple images. One is the centre, and many encircling it, each a little different from the other, yet they are all the same...One part of Mamman's life was almost like the rest of her life. What happened in the years recounted here continue for the rest of her life. Same patterns, same reactions. Only the situations were different. (Sandhu 182)

In Sandhu's novel, there is an attempt to legitimize the experience of the person living with mental illness and the caregiver. The intrusion of the past into the present through the narrator's repeated encounters with the sepia tinted photographs and his mother's letters are the elements from which the narrator tries to reconstruct the past. To sum up, Amandeep Sandhu's *Sepia Leaves* delves into the complex interplay of embodied narration and selfhood, presenting a powerful multilayered narrative, with the protagonist serving as both the narrator and a character within the story. This narrative approach allows for an understanding the embodied experience of selfhood, as the narrator grapples with his own identity while recounting the experiences of his family. Sandhu skillfully incorporates the subjectivity of memory into the narrative. The text highlights how personal recollections and experiences can shape one's sense of self, emphasizing the idea that memory is a crucial aspect of selfhood. *Sepia Leaves* offers a phenomenological exploration of how individuals experience and interpret the world through their bodies. The characters' sensory perceptions and emotions are closely linked to their self-identity. The novel delves into the temporal aspect of selfhood, emphasizing how the past, present, and future influence one's sense of self. Memories of the past, in particular, have a lasting impact on the characters' self-identities. In *Sepia Leaves*, Amandeep Sandhu skillfully weaves together textual and phenomenological elements to create a narrative that delves deep into the intricacies of selfhood, embodied experiences, and the impact of mental health on personal and familial identities making it a profound exploration of the human condition.

**Identity, self-perception and mental illness in Jerry Pinto's *Em and the Big Hoom*.**

Jerry Pinto is a poet, short story writer, novelist, translator and a journalist who is based in Mumbai. He is one of the foremost writers addressing mental illness in literary works and his *Em and the Big Hoom* (2012) is a pioneering work in this direction. Apart from this very significant work, he has written *A Book of Light: When a Loved One Has a Different Mind* (2016) which contains a number of short stories by Indian writers on mental health issues. He has also translated Swadesh Deepak's *Maine Mandu Nahi Dekha* to English as *I Have Not Seen Mandu*. Pinto particularly writes about how the experience of living with mental illness is different across cultures and socio-economic backgrounds. He is a strong advocate for improving mental healthcare services in India. Jerry Pinto has called for better access to mental health treatment, greater funding for mental health programs, and more awareness campaigns to help reduce the stigma associated with mental illness. The plot of *Em and the Big Hoom* is inspired by Pinto's own experiences of living with his mother's bipolar disorder. The plot of his novel centers around a Goan Catholic family in Bombay- Em (Imelda), The Big Hoom (Augustine, Em's husband) and their two children. The narrator of *Em and the Big Hoom* is not explicitly named in the novel. Pinto refers to the narrator as "I" or "the son" throughout the novel. Pinto's novel has a distinctive narrative structure. It is written in the first-person perspective of the unnamed narrator, who is the son of Em and the Big Hoom. Pinto's novel is structured in an episodic and non-linear manner. The narrator recounts various episodes and memories from his life, offering glimpses into the past, which are not necessarily presented chronologically. This approach mirrors the way memories resurface in one's mind and contribute to the understanding of the characters and their lives. The novel primarily consists of the narrator's personal reflections and recollections. He shares his thoughts, emotions, and memories, creating an intimate and emotionally charged narrative. The narrative alternates

between the narrator's personal experiences and his attempts to understand and empathize with the struggles and mental illness of his mother, Em. This duality in perspective provides insight into the challenges and complexities of living with mental illness within a family. The narrative weaves between present-day reflections and memories of the past, allowing the narrator to revisit key moments in his family's history and their interactions with Em's condition. This blending of time frames contributes to a rich and layered understanding of the characters and their experiences. Pinto's use of anecdotes, flashbacks and flash forwards, digressions, recollections, letters and photographs are the narrative devices through which he describes the lived experience of mental illness in his novel. It also explores the impact of mental illness in the family and how it affects family dynamics. Em's mental illness takes a toll on her physical health as well. Her manic and depressive episodes lead to exhaustion, weight fluctuation and other bodily symptoms. Her body indeed becomes the battleground of mental illness. Her medications have profound effect on her body thus impacting her interpersonal relationships. In one of Em's initial conversations in the text with her children centred around birth and psychoanalysis, Em affirms that, 'It's knowledge, knowledge is good, it will help, knowledge always helps' (Pinto 9) which she ironically comments regarding her family's knowledge of her mental illness. The novel portrays Em's mental illness as a deeply embodied experience. Em's emotional and psychological turmoil is manifested in her physical body. Her erratic behaviour, self-harm, and suicide attempts show the fusion of the mind and body in her suffering. Em's mental illness also challenges conventional notions of selfhood. Her sense of self is fluid and fragmented, which is reflective of the problematization of conventional notions of selfhood as stable and unitary. The novel portrays how one's embodied experience can profoundly affect their sense of self. It explores the phenomenological idea that our sense of self is constructed through our experiences and perceptions. Pinto's novel also examines the interconnectedness of selves in the context of the family. The family members are profoundly

affected by Em's mental illness, and their sense of self is influenced by their relationships with her. The narrator writes that he belongs to a family "where something was always amiss and it had something to do with his mother and her nerves. The nerves inside Em's head ran uncontrolled- flashing and sizzle-ng" (Pinto 10). The narrator writes:

Thoughts, like electric currents, and inside my mother's head they ran uncontrolled-flashing and sizzling. I carried that image with me through my childhood for what ailed my mother and took her to hospital, sometimes every few months. Then she gave another. (Pinto 10)

The narrator uses the metaphor comparing thoughts to electric currents-flashing and sizzling which suggests the intense and turbulent nature of the mother's mental illness. Mental illness, especially disorders like bipolar disorder, can manifest in episodic or cyclical patterns, making it challenging for both the individual and their loved ones to anticipate when symptoms will worsen. It portrays mental illness as something that is not just abstract but something deeply felt and experienced in the physical and emotional sense. In the succeeding section, after acquiring Em's diary, the narrator describes how Em (Imelda) and The Big Hoom (Augustine) get to know each other. But the narrator does not have access to Em's diaries while she was alive. The narrator often finds himself in the position of the inquisitor, the interrogator, demanding verification, corroboration and further proof while listening to Em's stories (Pinto 27). It stems from his desire for clarity and authenticity in Em's writings. The stories of Em would always open a new territory for the narrator:

Conversations with Em could be like wandering in a town you had never seen before, where every path you took might change course midway and take you with it. You had to keep finding your way back to the main street in order to get anywhere. (Pinto 26)

The narrator is constantly on the lookout for clues in Em's narratives for the possible cause of her nervous breakdowns. As the narrator writes, "...But each time Em told me something about her life, I would examine it for signs, for early indications of the 'nervous breakdown'. It was

an obsession and might have something to do with my curiosity about her life” (Pinto 32-3).

He believed whatever Em told him which is almost like an act of faith. He writes:

I tried to believe Em in everything she said. It was my act of faith, because I could see how the outside world immediately discounted whatever she said. But I wanted so hard to believe that I often found myself in the position of the inquisitor, the interrogator, demanding verification, corroboration, further proof. Most of the time, she didn't seem to mind. (Pinto 27)

The narrator finds himself in the position of an inquisitor when interacting with his mother, Em, because he is torn between his deep desire to believe and support her and the societal tendency to doubt or discount the words of individuals living with mental illness. The narrator describes his belief in Em as an “act of faith.” He wants to trust her, to be supportive and understanding, and to believe her experiences and feelings. However, he is also aware that he sometimes has to play the role of an inquisitor to seek further evidence or confirmation to protect her from external doubt and scrutiny. In the novel, the narrator describes Em as having a natural flair for writing, but she is not taken seriously, and she does not have the desired audience. As the narrator reflects:

Em wrote. She wrote when she was with us. She wrote when no one was around. She wrote postcards, she wrote letters in books, she wrote in other people's diaries, in telephone diaries, on the menus of takeaway places. Did she really want to be a teacher? I ask myself now. Or did she want to become a writer? In some of the letters she wrote Augustine, she was obviously flaunting her ability to write. She was demonstrating her charm, her effortlessness, her skill. She was suggesting to the world that she be taken seriously as a writer. (Pinto 45)

She destroys much of her writings herself which makes the narrator wonder whether her writing ability was a manifestation of her psychiatric condition (Pinto 45-6). The narrator is consistently on the lookout for patterns and reasons behind Em's mental health condition- in her diaries and notes, without much avail. Em acknowledges that the consumption of medicines for her mental illness is affecting her physical health. She always feels being in a dream-like

situation and the inability to comprehend the surroundings around her. Throughout her childhood, Em has the intuition that she might go mad because of the irrational fears she has—the possibility that she might rejoice at the death of her mother and sums involving Vernier callipers etc. The narrator finds it hard to come to terms with the alternating and sudden shifting moods of Em. The narrator describes that he cannot comprehend his mother because of her shifting moods and the physical manifestations of her condition. As he writes:

Suddenly, your mother steps into a patch of quicksand. The world continues to be idyllic and inviting for you but your mother is being sucked into the centre of the earth. She makes it worse by smiling bravely, by telling you to go on, to leave her there...Some part of you walks on and some part of you is frozen there, watching the spectacle... The only way to deal with such pain is to blot it out. My mother is now in a state in which her mind tortures her. It will not even lead her sag in apathy. Sometimes I see her body twitching a little in pain. Sometimes I see her forcing herself into a rigid stillness. Nothing will help her answer whatever savage questions her mind is asking.

(Pinto 59-60)

The description of the mother stepping into quicksand, while the world remains idyllic for the narrator, symbolizes the sense of isolation and emotional struggle that individuals with mental illness often experience. She is being sucked into a dark and isolating place, representing the internal turmoil she is going through. Her mind is described as torturing her with relentless questions and pain, making her body react with twitching and rigidity. The narrator feels that the only way to deal with the indescribable pain of Em is to share her story with people. The narrator often expresses his displeasure over Em's mother's efforts to pacify Em or explain the logical sense of the matter during her manic phases. One of the primary causes of Em's mental breakdown is her family's displacement from Burma which Pinto identifies early on in the novel. This episode is narrated to him only through his mother's and grandmother's stories which becomes one of the means of culturally locating his mother's illness. And, according to the narrator, "Em did not have the standard attitude towards motherhood. She often used the word with a certain venomousness, as if she were working hard to turn it into an insult" (Pinto

51). With that said, the narrator finds it difficult to trace it as one of the sole causes of his mother's illness. Apart from the voice of the unnamed narrator, there are dialogues between Em and her children and Em's husband, friends and parents. The central character of Pinto is fragmented, unsure, insecure, paranoid and the narrative voice of the novel oscillates between first-person narration, and a mix of other voices. The narrator expresses that

Depression means nothing more than the blues, commercially-packaged angst, a hole in the ground; until you find its black weight settling inside your mother's chest, disrupting her breathing, leaching her days, and yours, of colour and the nights of rest  
(Pinto 70).

The narrator highlights the profound and far-reaching impact of depression, dispelling the notion that it is simply a fleeting sadness or a form of "commercially-packaged angst." It portrays depression as a heavy, all-encompassing force that can have a devastating effect on both the individual with the illness and their loved ones, draining the vibrancy from their lives and causing emotional and physical suffering. The narrator considers the idea of creating a support group for the caregivers but due to limited awareness about mental illness they receive few responses. Later on, when Em is sent to the psychiatric ward, the narrator writes that she does not protest but acclimatizes to the rhythm of the hospital which is a way of temporarily escaping external stressors, responsibilities, and triggers that exacerbates her mental health condition. The hospital environment provides a respite from the challenges of daily life. As the narrator notes:

Perhaps the rhythm of the hospital life, soothed her, suited her. Here, no decisions were to be made and no one expected you to be anything other than a survivor, lying on a somewhat grubby bed, waiting for the tide to rise again. (Pinto 202)

The narrator details Em's life before her marriage and tries to unearth the various correspondences between his parents prior to their marriage. He produces many of these letters verbatim in the text before justifying the veracity of his claims. Most of the important sections of the novel are presented in the form of a dialogue between the narrator and Em. In the



concluding section of the novel, the narrator acknowledges that he was taught to view his mother as someone who is suffering from a mental illness, experiencing a nervous breakdown, or being “mad.” However, he comes to accept this reality in a positive way, realizing that the term “madness” is commonly used in everyday language to describe mental health issues.

Mad is an everyday, ordinary word. It is compact. It fits into songs. As the old Hindi film song has it, M-A-D, mad mane pagal. It can become a phrase- ‘Maddaw-what?’ which began life as ‘Are you mad or what?’. It can be everything you choose it to be: a mad whirl, a mad idea, a mad March day, a mad heiress, a mad mad mad mad world, a mad passion, a mad hatter and a mad dog. But it is different from a mad mother.

(Pinto 208)

The narrator suggests the importance of embracing the word “Mad” and its diverse connotations in a positive manner. The narrator underscores the complexity of mental health identities and the need for a more nuanced and compassionate understanding of mental illness beyond the simplicity of everyday language. Nevertheless, the narrator is never able to fully comprehend his mother until her death. As he writes:

...Underneath the mysteries continued, unchanged. Underneath, somewhere the chemistry of her brain, there was something that could not be reached. I was always aware of this.

(Pinto 216)

Pinto thus provides Em with a voice that is heard and interpreted by the narrator without attaching a pathological sign to it. The act of listening on the part of the narrator entails our ethical responsibility as readers and listeners of the mentally ill person’s narrative. Pinto interjects autobiographical material, fiction, digressions and repetitions for several reasons. Pinto’s use of autobiographical material adds an element of authenticity to the narrative. The novel is based on Pinto’s own experiences, including his mother’s struggle with bipolar disorder. Digressions and repetitions enhance the emotional impact of the narrative. These elements mirror the fragmented and complex nature of the mental health experience. Repetition, for example, symbolizes the cyclical patterns of mental illness, while digressions

reflect the scattered thoughts and emotions that individuals with mental health conditions experience. Pinto's use of these narrative techniques may be a deliberate aesthetic choice to engage the reader on a deeper level. Em's memories become the potent ground for the reader to explore and understand the complexities of her life, particularly her struggles with mental illness and the impact it has on her family. Em's memories serve as a window into her world and her experiences, allowing the reader to gain insights into her thoughts, emotions, and the challenges she faces. In *Em and the Big Hoom*, the interrelationship between memory, embodiment, and selfhood is intricately woven into the fabric of the narrative. These three elements are interconnected and mutually influence each other, creating a complex portrayal of the characters' lives, particularly in the context of mental health. Em's memories of her past and the events that have shaped her are inseparable from her sense of self. Her recollections, at times, define her identity, as they are both a source of comfort and anguish. The novel showcases how memory can be a cornerstone of one's selfhood, and how selective or fragmented memories can impact one's understanding of their own identity. Em's memories and experiences are not only imprinted in her mind but also on her physical body. The toll of her mental health issues is evident in how they manifest in her physical embodiment. These elements coalesce to create a rich and complex portrayal of how one's past, physical presence, and sense of self are interdependent and shape the characters' experiences and relationships. To sum up, this chapter tried to argue how embodied experience of physical disability and mental illness allows authors to provide nuanced representations of characters with disabilities or mental illnesses. This authenticity attempts to create empathy, educate readers, and dispel stereotypes, contributing to more accurate and respectful portrayals of these conditions. I also tried to demonstrate how the embodied experience of disability and mental illness complicates the process of identity formation. In fiction, characters with disabilities or mental health challenges grapple with questions about who they are, how they relate to others, and how their

conditions shape their self-identity. In the next chapter, I try to argue how disabilities and mental illnesses often intersect with human rights issues. Human rights advocacy is crucial in addressing these issues, ensuring equal opportunities, and promoting the dignity and autonomy of affected individuals. Recognizing and respecting the selfhood and embodied experiences of individuals with disabilities and mental illnesses is integral to upholding their human rights. This includes acknowledging their autonomy and right to make decisions about their own bodies and treatment options. Ensuring accessible and inclusive environments and healthcare services is also a human rights imperative.



## CHAPTER FOUR

### **The self-reliant human subject: Narrativizing human-rights in Reshma Valliappan's fallen standing: My Life as a Schizophrenist, Preeti Monga's The Other Senses, Shivani Gupta's No Looking Back and Sarmistha Pritam's Sun on My Face**

**Wait**

**BY Keith P. Jones<sup>32</sup>**

What does it mean to have to wait for your humanity to be recognized?

What does it mean to have to wait for your life to be valued by others?

What does it mean to have to wait for others to deal with you equal in your own life?

What does it mean do I have to wait for others to recognize their own humanity?

We have tried for decades and decades to live in a world that wants us to wait...

We have tried for decades and decades and decades to live in a world without heat...

But we must wait.

We have tried for decades and decades and decades to move in a way in which we are recognized, even for those who don't love us...

But we wait.

We wait for intelligence to enter into one soul so they can see the value in others...

We wait for the earth to be recognized is the only place we have to call home...

We wait for doors to be made easy to open.

We wait for classrooms to embrace us fully.

We wait for love to find us and embrace us for the humans that we are. We wait we wait we wait...

We have carried this weight on our shoulders for decades and decades and decades...

This weight of hatred this weight of oppression this weight of ableism this weight of sexism this weight of misogyny this weight of racism this weight of depression this weight of despair...

So we wait.

We carry this weight as if it was a boulder made out of feathers.

We carried this week as if it is the most-heaviest thing the universe has placed on the backs ...

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But we move remove with specific and determined intent ...to not have to wait for our humanity to be realize or acknowledged.

So for those who wait at crosswalks with no curb cuts...

So for those who wait in the rooms crying because their identities are not being accepted...

So we wait for those who need support and was seeking a better life...

So we wait for those who will make the change that we've all been waiting for...

But we're here now, so the wait is over.

Keith P. Jones' poem underscores the importance of literature and storytelling in shedding light on disability issues and advocating for human rights. The repeated notion of having to wait for one's humanity to be recognized highlights the injustice and dehumanization that marginalized groups often face. In literature, stories and narratives are powerful tools for human rights advocacy, as they can help bring attention to the struggles and injustices that people endure, ultimately seeking recognition and empathy. The poem questions why people have to wait for others to recognize their own humanity, suggesting that a lack of empathy and understanding is a significant barrier to human rights. Literature can play a crucial role in fostering empathy and helping individuals recognize the shared humanity of all people, regardless of their backgrounds. Keith P. Jones highlights various forms of oppression, including racism, sexism, ableism, and others. It underscores the power of literature to address and challenge the injustices faced by marginalized groups, advocate for human rights, and create a platform for shared narratives and voices. By highlighting the weight of oppression and the persistent struggle for equality, the poem aligns itself with the broader conversation on human rights and social justice.

This chapter seeks to illustrate how the proposed life-writing texts serve as powerful tools for advancing the cause of human rights, particularly in the context of individuals facing physical disabilities and mental illnesses namely Reshma Valliappan's *fallen standing: My Life as a Schizophrenist* (2015), Sarmistha Pritam's *Sun on My Face* (2014) Shivani Gupta's *No*

*Looking Back: A True Story* (2014) and Preeti Monga's *The Other Senses* (2012). I submit that, these texts serve as crucial signposts for human-rights advocacy in the face of the vilification and stigma. The aforementioned life-writing encompass diverse modes of storytelling by a human right debarred narrator with an emphasis on experiential life as its starting point. These modes range from autobiographies, memoirs or email conversations that document human-rights violations at various levels. Sidonie Smith and Kay Schaffer opine "that modes of personal storytelling vary depending on whether the contexts of telling are juridical, political, communal, social, imaginative or some overlapping condition. Since personal storytelling involves the act of remembering, of making meaning out of the past, there are different registers of truth beyond the factual- psychological, experiential, historical, cultural, communal, and potentially transformative".<sup>33</sup> Smith and Schaffer further note that "the 'present' of personal narrating becomes a fulcrum, the point where the pressure of memories of a traumatic past and the hopes for an enabling future are held in balance. As balancing acts, directed back to a past that must be shared and toward a future that must be built collectively, acts of personal narrating can become projects of community building, organizational tools, and calls to action".<sup>34</sup> In the previous chapters, I attempted to examine how certain life-writing and fiction serve as important therapeutic counter-narratives by foregrounding an embodied nature of selfhood, subjectivity and agency and the importance of caregiving. The texts selected for analysis in this chapter serve as human-rights advocacy narratives promoting and encouraging empathy, inclusiveness and social change. They problematize the unequal treatment of the disabled and mentally ill subject across various institutions. The aforementioned narratives also raise certain ethical dilemmas and moral questions such as the ethics of individual choices, societal norms and the pursuit of justice. They also attempt to question the nature of power and authority,

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<sup>33</sup> See Kay Schaffer and Sidonie Smith's "Introduction" in *Human Rights and Narrated Lives: The Ethics of Recognition*. (8)

<sup>34</sup> Ibid.

including how those in positions of authority may abuse their power or act in ways that infringe on the rights of others. Anthony Langlois opines that, “human rights are...rights generated by narratively rationalized metaphysical beliefs, beliefs, which informs us as to what the metaphysical category “human person” means” (Langlois, 369). Generally, in human rights campaigns, the idea of ‘storytelling’ occupies a central position. Scholars working in the field of human rights emphasize that stories in which the rights of the human subject are violated and debased, be told. (Slaughter 2007, Dawes 2007 Anker 2012). Pramod K. Nayar sees literature as a cultural discourse where certain ideas about the essence of humanity are explored. He further observes that such conversation can take two distinct paths when it comes to defining what it means to be human. The first path follows a narrative tradition that documents the growth and development of individuals, as seen in genres like the sentimental novel or bildungsroman (67). This chapter, however, primarily concentrates on the second path, which delves into a narrative tradition portraying individuals who are fractured, deprived, and dehumanized. It specifically explores those who have been marginalized and stripped of their human identity. Tobin Siebers writes that:

It is vital... to reconsider our philosophical ideas about humanness because democracy will have no legitimate basis for being the open society it claims itself to be without a generous and metacritical concept of the human, one that gives people with disabilities a place in the public forum. (93)

Judith Butler, similarly points out, there is not “a human condition that is universally shared,” such that certain people “cannot be humanized, [for] they fit no dominant frame for the human” (20,34). This notion on what constitutes the human status has been the subject of enquiry among many disability scholars and those working in the field of mental health and well-being. Jasbir Puar insists on “inviting a deconstruction of what ability and capacity mean, affective and otherwise, and to push for a broader politics of debility that destabilizes the seamless production of abled-bodies in relation to disability” (166). The observation of the scholars on

human rights cited above is not merely to privilege one over the other, but to reconsider the ideas of what constitutes the ideas of the human subject, humaneness and humanity. The act of storytelling across contexts bear witness to various values, experiences and ways of understanding the world and they devise ways to respond to injustices and forms of suffering. Over the last few decades, life-writing have been the most powerful force for positing human rights claims around the world. Life-writing on displacement and cultural marginalization are not the only narratives to foreground the ideas of citizenship and belongingness but disability and mental illness narratives have been equally compelling in advancing an alternative worldview on human rights. Narratives of disability and mental illness draws attention to the failure of nations to fully address the concerns of the physically and mentally disadvantaged groups. Sidonie Smith et. al opine that

... human rights as the privileged mode of addressing human suffering and the rise of popularity of published life narratives- have commonly been understood to exist within the separate domains of politics and literature, respectively. However, literature and human rights in concert with more recent interdisciplinary studies, understands “the political” as inclusive of moral, aesthetic, and ethical aspects of culture. It treats life narratives and human rights campaigns as multidimensional domains that merge and intersect at critical points, unfolding within and enfolding one another in an ethical relationship that is simultaneously productive of claims for social justice and problematic for the furtherance of this goal. (2)

The proposed life-writing under discussion in this chapter not only narrate personal experiences but also delve into broader ethical and moral questions related to disability, mental health, and human rights. The ethical relationship described in the observation highlights the potential for these autobiographies to be productive in the pursuit of social justice.



## Embracing the Other: Mental illness, human-rights and social action in Reshma

### Valliappan's *fallen standing: My Life as a Schizophrenist*

Reshma Valliappan, also known as Val Resh, is an author, activist and artist known for voicing her concerns on disability, sexuality, mental illness and human rights. Her documentary “A Drop of Sunshine” appeared in Public Service Broadcasting Trust, which describes her struggles and ultimate recovery from schizophrenia without the use of medications, a topic that has generated significant controversy. She is also the founder of “Mind Arcs” which runs an initiative called “The Red Door”, a platform which uses social media and blog writings to shape public attitudes about mental health issues. Reshma Valliappan defines schizophrenia as “a communication of the voices and visions I hear while interpreting the metaphors and symbols I experience. I have learnt to experience the visions and voices with confidence. My “symptoms” haven’t changed but my reaction to them and my ability to translate them for others has- through my writing, art and public speaking engagements” (Valliappan 2). *fallen standing: My Life as a Schizophrenist* (2014) is her autobiography, presented in the form of a series of emails to her editor. In this book, she sheds light on various aspects of her illness, the stigma surrounding it, and human rights issues. She received a diagnosis of paranoid schizophrenia at the age of twenty-two. Within her autobiography, she shares her personal experiences of living with schizophrenia in India and Malaysia, as well as addresses the prevalent stereotypes associated with her mental health condition. With its experimental blend of a very fractured and self-reflexive postmodern narrative form and confessional content, Valliappan’s autobiography stands tall as vehemently advocating for the rights deprived to a person living with paranoid schizophrenia. In Valliappan’s autobiography, the narrator grapples with her “alterity” to comprehend the split nature of her subjectivity. The prevailing medical understanding of conditions like schizophrenia, or severe mental illness, often associates them

with lunacy, madness, incoherent speech, distorted thinking, violence, social isolation, and an overwhelming sense of purposelessness. This depiction is challenged in her autobiography. Schizophrenia, as a medical disorder, has been relegated to the realm of the unknown and the enigmatic, rendering the experiences of individuals with schizophrenia as deviant. The publisher's note in Valliappan's autobiography clarifies that the book does not adhere to the conventional structure of an autobiography with a clear beginning, middle, and end. Instead, it is presented as a series of emails, text messages to friends, and correspondences. Certain sections of the book consist of ramblings describing the narrator's hallucinatory and delusional states of mind. The pauses, interruptions, and erratic narrative flow are all intentional elements of the author's attempt to convey her story, without imposing any specific "order" upon it (v). Narrative devices like pauses, breakdown of language and meaning mirror her fragile mental health. The fragmented nature of the narrative is a reflection of her fragmented mind and emotions adding complexity to the narrative. The style of the narrative is candid and honest which does not shy away from portraying her vulnerabilities and struggles. In the Preface to her autobiography, Valliappan begins by informing that the first instance of her discrimination occurred at a mental health facility. She writes:

I remember my first experience of discrimination which occurred in the very place that was supposed to understand people like me. I was 21. I had gone in for a psychological testing for some of the seniors who studied psychology. There was a range of experiments they wanted me to participate in, such as problem solving, memory, attention span, etc. I completed the experiments before the minimum time limit and came out. The report was, 'We can't use her scores, they are not normal.'... Years went by. I was given treatment, attended support groups, yet was caught in a vicious circle, for not only was I discriminated against, my entire family was too... (Valliappan ix)

Valliappan cites several instances of human rights violations by highlighting the discrimination, stigmatization, and the broader negative consequences that she and her family faced due to her perceived differences. It emphasizes the importance of addressing such violations to ensure

that all individuals are treated with equality, dignity, and respect, as guaranteed by human rights principles. At the mental health facility, she is diagnosed with paranoid schizophrenia because her test results do not adhere to certain acceptable standards set by the institution for sane human behaviour. This seems to suggest that the protagonist, Reshma, is diagnosed with paranoid schizophrenia based on criteria established by the mental health facility. The institution uses specific standards or benchmarks to evaluate patients' behaviour and symptoms, and Reshma's test results do not meet these criteria for what is considered "normal" or "sane" behaviour according to the institution's framework. This diagnosis reflects the medical model's approach to mental health, where conditions are categorized based on observable symptoms and behaviours rather than a deeper understanding of individual experiences or social contexts. The memoir explores how such diagnoses can be limiting or stigmatizing, shaping individuals' perceptions of themselves and their experiences within the mental health system. Following this, she has to undergo treatment for many years which do not produce any desirable results, and she and her family continues to face stigmatization and social isolation in different ways. Through her narrative, she tries to dispel the misconceptions surrounding schizophrenia which is seen as synonymous with madness, incoherence, pitifulness, uncontrolled sexual drives, amongst others. In the concluding section of her narrative, after years of living with the disease, she accepts herself as a person. Over time, she gains a deeper understanding of her condition and how it affects her. This self-discovery and to self-acceptance as she becomes more in tune with her own experiences and emotions. The narrator informs us that her psychiatrist and counsellor wanted her to create awareness about living with schizophrenia. But the irony of it is that the system itself is responsible for labelling her a schizophrenic in the first place. Her medical diagnosis as a schizophrenic person leads to the violation of her basic rights as a human being such as the right to vote, right to the same education, right to sign a contract, the right to hold office etc. Due to her illness, Valliappan is

not able to maintain a balance between her inner demons or turmoil and the outside world. She writes:

...First the mind screws up and the world is still on the brink of accepting such mind screws. Then there is this body which has a life of its own. I really do feel like an alien trapped in this human body and therefore having to experience all this readjustment...

(Valliappan 4)

Valliappan's autobiography is written as a series of emails to her publisher- Ritu Menon. The first email reads like a reply to an advice given by the publisher. In the email, she describes the series of hallucinations and disassociations she has to withstand during her recovery from a brain tumour. She clarifies that a person with schizophrenia may develop other neurological anomalies while the vice-versa is not necessarily true. Reshma further describes her seizures, self-harm tendencies and situations when her body goes numb and moments when she feels the need for seeking help. Soon after, she loses her awareness of people and her surroundings. In a series of emails to her publisher, she writes:

Dear Ritu,

I am in a state of giving up all over again. I've tried my best to reach out to those whom I normally speak to, but it's another mask I wear even with them. At least during these moments that is the case, and once I regain myself, I do speak. But that has not been the situation the last couple of months. I find myself withdrawing more often than I did... I find myself more depressed internally. It seems nothing really matters anymore. Not my recovery, not my work, not my studies, not my art, not my writing, not this book, not any future plans I have made and continue making, in order to build responsibility at my subconscious and conscious levels so that I don't take my life again.

(Valliappan 7)

In the passage quoted above, Valliappan expresses feelings of depression, withdrawal, and a sense of hopelessness to her publisher. Valliappan mentions that they are wearing a mask even when talking to people they normally speak to, indicating a sense of hiding their true emotions and struggling with their mental health. Literature on human rights describe ideas about rights

and justice, and life-narratives of Valliappan, Pritam, Monga and Gupta offer powerful personal narratives that shed light on the lived experiences of individuals, often touching upon themes of resilience, adversity, and the struggle for justice and human rights in the face of personal challenges. As Richard McKeon writes, “the history of human rights must be rewritten, at every stage of its progress, from the point of view of ideas and values, the philosophy, of that period” (9). Ranciere writes that “a ‘literary community’ is not just a community of writers, readers, publishers, and critics: it is a community that identifies with the forms of being human made possible by narrating one’s experience of violation of rights- which is perhaps, the only means by which equality, dignity, autonomy become common sense” (9). In a confessional tone, the narrator of Valliappan’s autobiography describes her existential crisis to her publisher and what prevents her from leading a normal life. Her sober and manic selves are completely at variance with each other. For her, it is a disembodied experience. She experiences extreme confusion and paranoia, further contributing to a sense of being disconnected from the world. She perceives threats or conspiracies that are not based in reality. As her psychiatrist describes, it is almost like a “Catch-22” situation inside her head which cannot be easily deciphered (Valliappan 8). The narrator describes her loss of grip over the world, the existence of several voices inside her head and constantly shuffling between two opposing conditions within her mind. The narrator writes to her publisher that the moment she thinks about her past, all traumatic memories come rushing back. She notes:

I have tried procrastinating writing to you. It means letting someone in. Which I am not used to and very rarely allow myself to do. It means having pieces of my past resurfacing which I have conveniently buried... some of which I don’t remember. I remember all the good times. But the minute I begin to recollect the ‘bad’ times, I become someone else. (Valliappan 8)

She mostly stays indoors for the fear of triggers that might set in if she ventures out. She is caught in a spiral of prolonged inertia where she is unable to act.

It has come to a point that I do not know me anymore. This feeling which is called ‘depersonalisation’ has happened many times before. But this time it’s a lot more intense. It really feels like a ‘takeover’. (Valliappan 10)

In her self-revelatory emails, she reaches out to her friend and publisher describing the effects of the prescribed drugs on her body. However, there are no coherent symptoms as they come and go at irregular intervals. At times, she has certain “drug-cravings” which cause her depression and suicidal ideations in the first place, but she is compelled to consume these drugs to manage her body convulsions. She describes the prejudices and discrimination she experiences from people who perceive her as “schizo”, “psycho”, “crazy” and a “lunatic” (Valliappan 11). Through a series of flashbacks, she describes the memories of her adolescence which feel like “memories which are not hers anymore” (Valliappan 13). The narrator portrays her symptoms as originating from external, often mysterious, and at times even malevolent sources of “agency” that lie beyond the realm of her comprehension. Within Valliappan’s narrative, the individual receiving these thoughts is a passive participant when it comes to the symptoms arising from her condition. The disruptions and divisions within her mind, brought about by this condition, contribute to her feelings of anxiety and depression. She finds the very act of narrating her past that is laden with the germ of trauma and abuse, depersonalizing. She recalls an incident from the year 1995 when she is taken to a doctor because according to many, she was in dire need of help. The doctor suggests that the problem lay in the fact that Resh is a boy trapped inside a girl’s body or a transvestite as he called her, which is, he believes, causing the seizures and body convulsions. The doctor apparently has a cure for her condition: “There is therapy for this and once you are 18 you can decide if you want to go in for a sex change. There are plenty of people like you” (Valliappan 15). Although the diagnosis seems bizarre, the narrator does talk about her wish to dress up as a boy and her antipathy towards dressing up as a girl which her family wants. Prior to the doctors’ visit, she describes an incident which is

primarily responsible for her ailment- an incident in which she runs away from her house disguised as a boy. She describes the hatred she eventually develops towards the members of the family for their attempts to discipline her. She is suicidal and once she slit her wrists to free herself from her family. She writes:

I felt like killing myself so often. I began cutting myself and it soon turned into a habit. I would cut myself because the pain just made me feel free. Blood oozing out made me feel alive and liberated. In a way, metaphorically, I wanted this 'family' blood to disappear. I didn't want that blood. Couple of my friends noticed it but didn't say anything. Some encouraged it and did it too. I didn't like doing it in front of them. So, every chance I got when I was thrown out of the class I would return to the same bench and slash myself. (Valliappan 18)

She suggests that her psychiatric disorder is rooted in a concrete cause- the inability of her parents to accept her unconventional expressions of femininity- compels her to share her story. Recounting an incident from her childhood, she writes that she ran away from home in search of an unknown destination. The only thing that is clear to her is that a road lies ahead, an option that holds better prospects than living with her family. In the road there are constantly patrolling policemen at a time when the "trade of heroin flooded the streets of Malaysia and almost all the HIV/AIDS cases we had were caused by shared needles and prostitution" (Valliappan 36). With great difficulty, she also describes the sexual encounter with the drug peddlers on the streets- an incident recalling and narrating which causes her much trauma. As she writes:

It was years later that I figured what that feeling was. That drug. It became an addiction. My very own addiction. I knew what it was and I know what it is now. Ever since then I kept looking for a dragon... and when I found it, I kept chasing it. Kept chasing the dragon. I still feel its fire within me, burning right through me, making me fly... there are days I look for it still. I look for the dragon. (Valliappan 38)

Valliappan uses the phrase "chasing the dragon" which is a metaphorical expression commonly associated with drug use, specifically heroin. The "dragon" represents the intense and euphoric high that comes from using heroin. Valliappan is using this metaphor to describe her addiction

to the drug, how it initially made her feel, and how she continues to yearn for that feeling even after experiencing the negative consequences of drug addiction. The narrator describes the profound impact of drug addiction in her life and her ongoing struggle with the desire to recapture the initial euphoria that heroin provided, despite the destructive consequences it brought into her life. The narrator emphasizes the existence of a self, other than her sober self after the onset of schizophrenia. The fact that she is able to exercise autonomy and take decisions independently from the challenges posed by her disease, implies that, notwithstanding the great suffering schizophrenia causes, it does not obliterate her sense of identity. The incident triggers her to the extent that it makes her a nocturnal person. She is placed under house arrest and all her “boyish clothes” are discarded to prevent any such transgressions in the future. The family that is steeped in superstitions, takes her to a priest-cum-doctor who diagnoses her with Reye’s syndrome- a brain issue caused by an overdose of aspirin. The next remedy is to take her to the nearby temple to seek blessings of a godman. That meeting with the godman changes her fundamental understanding of spirituality. As she writes:

...that became a turning point in the understanding of spirituality. It brought together my ‘symptoms’ and cravings and my weird encounters with the dead. It gave me the balls to throw the story back at my Dad and tell my folks to reconsider my experience of schizophrenia and why I should not be on medications- they were damaging me more than helping. (Valliappan 56)

Valliappan felt that the medication she was prescribed for her condition was doing her more harm than good. This could be seen as a potential violation of her right to appropriate and effective medical treatment for her mental health condition. Her family recounts to her a story of the “aghorī tantrik”- a devotee of Goddess Kali. She is awed by the image of the great mother figure who exhibited this “demonic vampirism” (Valliappan 56). She is curiously drawn towards this darkness and her obsession with the dead. Soon she embarks on her “Shaktipeeth”



visits to understand the connection between death, life, addiction and obsession. He writes a poem with the Mother Goddess as the muse:

Mother, let me drink of you  
 ...if death was a passing phase it would be a manipulative face if hunger was to live it  
 would be a momentary state...  
 if thirst was to hope it would be a reason to let go...  
 ...  
 And She said  
 As you walk, the earth will move with you...  
 as you breathe, the wind shall be thy guide...  
 as you churn deep within, fire shall burn just the same...  
 and as your mind floats all universes,  
 water shall transform as desired...  
 why then do you ask for my appearance, child?

(Valliappan 57-59)

The narrator attempts to channel the essence of destruction and annihilation embodied by the Goddess. She expresses her admiration for the Goddess's relentless vampiric nature, which refuses to yield to any force. The narrator is determined to disrupt anything that obstructs her comprehension of the world. She is on a quest for the unfamiliar and seeks to uncover the significance of her "madness" within the enigmatic presence of the mother goddess. In an interview, she opined, "I call myself the 'schizophrenist,' and my mission is to destigmatize madness by presenting it as a unique way through which some people assimilate meaning in the world, using all their various senses" (Valliappan 5). In a section of Valliappan's narrative, when conveying these ideas to her publisher, the pages of her story are filled with repetitive words, indicating a breakdown in language and her struggle to communicate in coherent sentences. In an email correspondence to her friend and editor, the narrator writes:

Alone, Alone, Alone, Alone, Alone, Alone  
 Alone, Alone, Alone, Alone, Alone, Alone  
 Alone, Alone, Alone, Alone, Alone, Alone.

(Valliappan 60-62)

In the course of her correspondence with her publisher and friend, he loses her ability to communicate in full sentences because of her mental triggers. This repetition emphasizes the emotional and psychological state of being completely alone, possibly reflecting her feelings of alienation or disconnection from others. Following her return, her parents implement stringent measures to discipline her. While narrating the events, she feels her “teenage self” venting her frustration by attempting to construct a narrative of her life. People often misinterpret her condition as multiple personality syndrome and her psychiatrist advises her to go through the works of R.D Laing on the divided self. She constantly writes about her fascination with blood and pain and about her self-harm tendencies (Valliappan 69). Her obsession over a thing gives her a “memory advantage over things so that even if there was a mess, I would notice that something was missing from it...” (Valliappan 69). At one point, she is on the verge of completely losing her grip with reality and she decides to stop writing. She notes:

...It came to a point where I stopped writing my journals, would only write on tiny bits of paper- roll them up and hide them under my study table. But somehow, she found them too- which drove me further nuts because she obviously made such an effort to look through the pile of mess there was, including moving my table, to find it eventually. I finally stopped writing as I couldn't find a single spot she hadn't touched or searched. (Valliappan 70)

In Valliappan's narrative, the narrating “I” is both the “I-witness” and “eye-witness” (Smith and Watson 2017). The narrating “I”, in the case of Gupta, Monga, Valliappan and Pritam tells the story of an activist, but also that of a bigger community of oppressed people and these texts “invariably contend that theirs is an individual voice that stands for a collective self” (Martinez Garcia, 2017). In Valliappan's autobiography, the narrator revisits the moment she is sent off to a “Fixing Camp” meant for ‘spoilt-kids’. The narrator asserts that writing about the

experiences at the fixing camp has created a storm within her. The experiences that she encounters at the camp are almost uncanny. As she recollects:

It seemed I was walking a mile while there were eyes glaring at me and voices talking about me. I approached my table and sat down. My friends didn't ask me anything...Grown-ups don't know the kind of damage they can do even if there are good intentions behind what they do...In my understanding it seemed that the so-called 'maturity' in them destroyed all possible grounds for them to understand what being immature or childlike or growing up is. (Valliappan 71)

She is allotted a room with no exit doors and the purpose of the camp is to discipline her by breaking her rebellious spirit. At the camp, her gender identity is questioned by the instructor because it does not conform to conventional standards for a girl's appearance which is a violation of her right to express her gender identity as she sees fit, which is a fundamental aspect of the right to self-determination. After her return from the camp, she discovers that her "boyish" clothes are given away and is replaced by clothes that are deemed fit for a girl according to her parents. She considers this new image to be abominable. Soon after, she is sent off to another camp from her school which will "help her study and get disciplined in preparation for the finals" (Valliappan 92). This infringes her right to make choices about her life and personal development. This camp is no less than a military training center in which strict disciplinary regimes at controlling the mentally ill. The training center had "tuned them into robots in just one week" (Valliappan 87). Such instances described in her autobiography raises concerns about the rights of individuals with mental health conditions. Coercive measures and attempts to change her behavior through such means infringes upon her rights to appropriate and humane treatment, as well as her right to live with dignity. The narrative alternates between sections narrated by the older self and the fifteen-year-old narrator. The experiences gathered at the camp, as the narrator notes, already strains much of her "sanity" and creates a memory block. She writes:

My mind had most likely already created a memory block owing to the previous camp my parents threw me into. I was finding it very difficult to focus on the words she was saying. It was all replaced by images running everywhere. She noticed that because I couldn't repeat what she said. I think I was always stoned by the ingredients of nature, and got lost in it. From the birds to the trees, the grass, the leaves, the sky... everything was too surreal for me. (Valliappan 101)

The problem, at the moment, is not so much about the disciplinary procedures at the camp as it is about rescuing herself from her disembodied and depersonalizing thoughts which emerges as a consequence. She is subjected to this due to her failure in meeting certain set standards of 'good' academic performance. The narrator describes the lack of appropriate mental health support. Her mental well-being is compromised due to her experiences at the camp, which is a potential violation of her right to access adequate mental health care and support. In the course of her narrative, she writes that she is discouraged from pursuing arts which is meant for "stupid people" (Valliappan 106), because of her inability to remain still and focused which, again, infringes upon her right to pursue education. Her creativity finds expression through rap music and rapping religious chants. Her parents soon decide to move to India since people did not accept her non-conformist attitude back in Malaysia. Their return to Pune amidst her relatives and a host of surveilling adults proves to be no less arduous and she is again questioned about her "tomboyish" attitude. Similarly, her admission to a school is denied due to her failure to exhibit certain "girlish mannerisms". Due to her apparent "tomboyish" appearance, she easily passes off as a teenage boy and is not questioned at the shop from where she buys a pack of cigarettes. She writes about her parents' discomfort regarding her decision of joining the basketball team for the same reasons. The process of narrating and writing about her life in the autobiography involves

...disassociation from every emotion and memory, often breaking into bouts of uncontrollable anger and pain. This is not as easy as I thought it would be. To remain truthful to that experience and let my Other write it is to make myself open and

vulnerable during the process. It's a very different trick on my skills. I am no more the observer as my body has to be occupied by the ego that writes. This is the only way I am going to remember. (Valliappan 134)

Valliappan frequently feels disconnected from her surroundings and thoughts. She emphasizes that the challenging nature of the illness makes her senses go numb, while also highlighting the uncomfortable questions about how society, including families and the medical profession, perceives and treats individuals with mental illness. In her email to Ritu Menon (of Women Unlimited), she further notes that she is caught in a headlong tussle with her alter-egos which often cloud her thoughts. She writes:

I have no clue where I'm going with this but I figured the word for what happens when one alter rapes the other. I believe the term is alternate sexuality- but under the given circumstances it means; my alter ate my sexuality. (Valliappan 144)

On the occasion of World Mental Health Day, Valliappan tries to demystify the conventional understanding of mental illness in the way psychiatrists try to frame it within their understanding of symptoms. She then writes a letter and dedicates it to mental health practitioners and carers when tending a person with mental illness. The narrator of Valliappan's autobiography, stepping out of the vulnerable state of being a victim, takes charge of her own life, and encourages others to raise their voices too. Rather than letting others speak, she is the one speaking for herself. She becomes an empowered individual in the process. Some of the things she describes include taking the subjectivity of the patient into consideration and listening to their stories before diagnosing them with a disorder. Much of the stigma she faces is due to the misconceptions of the people about the invisible nature of her disability, resulting in inconsiderate remarks from people often placing her in a Catch-22 situation. She writes:

So here I am... faceless. Just holding the chalice filled with the nectar of life and death. It's become irrelevant how I appear to you anymore. I've become a painting you have appropriately marked and auctioned... and lo! I thought I was the artist.

(Valliappan 152)

The autobiography frequently shifts between various facets of Resh's personality, including her adult and teenage selves, as well as her manic and sober selves. The narrator elucidates the factors contributing to her aversion towards her parents and their decisions, leading to early-onset of dissociative identity issues. These are some of the instances which still traumatizes her. At times, she wishes to be a mere observer of those events from the vantage point of the present and tries to expunge them from memory. She confesses these episodes to her publisher which is therapeutic to her. The second section of her autobiography starts with a journal entry titled "The Schizophrenist," which adopts a confessional tone. It starts by emphasizing that the medication not only suppressed her symptoms but also stifled her voice. Under its influence, she is more of an obedient dog who suppresses her individual choices. This suggests that her personal freedom and autonomy were restricted by the effects of the medication. Much of her anger is directed towards her family and relatives who did not accept the changes in her behaviour resulting from the illness. After narrating the first-hand experiences of living with schizophrenia, she pleads the readers "to throw the book away because my arrogant egoistic throbbing self will tell you to your face that maybe you're not worth reading the rest of it" (Valliappan 164) which suggests the complexity of sharing one's personal experiences, especially those related to mental health, and the vulnerability and self-doubt that can come with it. The narrator is expressing a hesitancy to open up about her experiences, possibly fearing judgment or rejection, and this plea to "throw the book away" could be a way of preemptively protecting herself from potential negative reactions. Valliappan's autobiography tries to educate people about the intricacies of her mental health condition who label a person as "crazy" and "insane" without paying much attention to the person's material realities. The paradox of schizophrenic existence is that people did not take her statements at face value because a schizophrenic person's mind is flooded with delusional and disorienting thoughts and paranoia. In one of her emails to Ritu, the narrator describes her inability to recognize her

image in the mirror and longs for the death. She withdraws from the society and herself due to the existence of multiple entities within her. She writes:

I respect their voices and I had to remain honest to them. After all they were the ones who were always there for me. In order to share, what I need to share, I see my separate selves as individuals in their own right and I will keep their privacy intact, as to how much they decide to be transparent about. (Valliappan 171)

By referring to her “separate selves as individuals,” the narrator acknowledges the multiplicity and complexity of her identity and experiences. This suggests an awareness of the diversity within her own self and the understanding that schizophrenia can present various facets of her identity. She recognizes that these voices or aspects of her experience may choose how much they want to share or be transparent about. For instance, the younger self narrates portions of her life while the elder self has to intervene and edit out the inconsistencies. By using this narrative approach, Valliappan is emphasizing the complexity and evolving nature of her life story, as well as the idea that our understanding of our own experiences can change over time. It allows her to present a more nuanced and reflective account of her life and her experiences with schizophrenia. Writing her autobiography is not her conscious choice but an act of doing justice to the experiences of the “guilty” self (Valliappan 174). She writes that in order to survive one must live a measured and calculative life. She writes “one’s emotions, feelings, thoughts and behaviour should be balanced and averaged out like in statistics, if one is found not at the median point then something is wrong” (Valliappan 176). Much of her attempts to negotiate childhood trauma, shame, abuse and accepting her own identity comes from self-training. She also necessitates the need to address internal conflicts within the family and mental health problems. According to her, the pain inflicted to her by the family found its vent in self-harm, which she calls Pain Therapy. Self-harm was the way by which she gained control of her emotions (Valliappan 180). In the section, “Dying to Breathe”, she begins by narrating a dream in which she is trapped in a man’s body and is jabbed with a syringe, which is an

allusion to her experiences on the streets when runs away from home. She explains that voices in her head have their own ways of communicating things to her in a language which is not easily comprehensible. This does not necessarily mean that persons with schizophrenia have the same set of symptoms. She then describes her visit to Toronto to attend a conference on schizophrenia which is one of the first acts of courage and self-confidence. She marks the twentieth anniversary of her running away from home and notes that the episode after her brain surgery contributed to her dissociative personality. She describes the agony of being a hostage to her mind thus:

It is beyond anyone's perception to 'see' the agony of the mind being chained, to see how you are a victim chained in your mind. Your soul is trapped, screaming from within to let it out, and you are consumed by so many voices that you do not recognize your own. You do not recognize the plea of your own soul. (Valliappan 208)

Adriana Cavarero's notion of the "narratable self" can be useful in understanding the life narratives of persons living with schizophrenia. Cavarero writes:

The narratable self finds its home, not in the conscious act of remembering, but in the spontaneous narrative structure of memory itself. This is why we have defined the self as narratable instead of narrated. Indeed, the particular contents- the pieces of story that the memory narrates with its typical and unmasterable process of intermittence and forgetting- are inessential. What is essential is the familiar experience of a narratability of the self, which, not by chance, we always perceive in the other, even when we do not know their story at all. (66)

Along the lines of Cavarero, the schizophrenic person can be said to have a "narratable self" "whether or not the language of the person makes any sense, it is understood to be working towards meaning, towards the story of life that is unique to the person, striving towards a unifying life-story" (33). At a certain point, Valliappan admits to pausing her autobiography as she felt it is wrong to document the intricate details of her journey as a schizophrenic person. But she feels the need to create awareness about people living with schizophrenia. Getting off the medicines is the first act of acceptance. She finally accepts herself as a schizophrenic which



enables her to connect with a set of people over social media who are keen to know about her health condition. Valliappan effectively uses the metaphor of the mountain to describe her experience of living with schizophrenia, which is a one-person journey in which there are “the side-effects of the climb and the nastiness of the fall” (220). She further writes:

The air can confuse you and force you into states of delusion and hallucination. There is nothing to hunt or eat. There is no land to rest on and set up a camp-fire. Even if you wanted to watch the stars you cannot rest while doing so. Such is the journey when one climbs the mountains of schizophrenia. (Valliappan 220-221)

Valliappan emphasizes the symbolism involved in the subjective experiences of the illness. Her first trigger occurs due to the high levels of toxicity in her body on account of her reliance on drugs, alcohol and cigarettes and her insomnia. This is during her regular visits to the college counsellor after her first diagnosis of schizophrenia. During those years, alcohol and drugs played a major role in her life. Under its impact, she could see through people’s inner selves. As Valliappan writes, during stages of intoxication, she could see through the bodies of people and the ghosts which are trying to break free. At the clinic and during her journey back home, she notices the awkward glances and smirks of people that made her loathe herself. Following the advice of her psychologist, she visits a psychiatrist who treats her for addiction. During this period, she thinks about various alternative modes of treatment and recovery. She calls her condition- “the alternate”- living with delusions and symptoms, and the process of recovering (Valliappan 241). Towards the end of her autobiography, Valliappan is thankful to the people who pass vile comments at her and are prejudiced towards her. She further exclaims that those comments magnified their own sense of jealousy, greed, lust, envy, pride, illusions and pretense (Valliappan 250). Under the influence of voices in her head, she feels physically exhausted after a point. It is during these manic phases that she starts painting which originates from the very place which made her crazy (Valliappan 253). With her father’s encouragement, she gradually embarks on the road towards recovery. She tries to capture the shades of her visions

on the canvas which is the only way to get them out of her sensory field. The narrator describes her difficulty in finding the appropriate idiom to describe the experience of madness as she believes it will create “word salads”<sup>35</sup> (Valliappan 257). One of the important aspects of her journey towards recovery and accepting herself as a schizophrenic individual is to treat her voices and every other being or entity she sees as individuals in their own right (Valliappan 258). The metaphorical language in schizophrenia is itself a very slippery terrain—undecipherable and enigmatic in itself. Valliappan seems to imply that the experience of living with schizophrenia can be challenging and mysterious, making it difficult to fully understand and interpret the condition because there is no unilateral understanding of the mental disorder. To sum up, Valliappan’s autobiography raises important questions about the self in relation to her debilitating disorder. In terms of the nature of the self, Valliappan’s narrative does not offer any definitive conclusions. She describes the symptoms arising from her disorder as an external force, an unfamiliar territory beyond her control. Nevertheless, these symptoms somehow enable her to manage her multiple selves and lead a creative and productive life. Valliappan’s uncertainty about her subjective experience of self-identities and the crisis in her sense of personhood reach a climax when she severs her connections with the world around her. Often trapped in a state of limbo, she no longer feels entirely human, as evident in her references to allusions and metaphors, which symbolize her struggle to comprehend both herself and the world. Incorporating images and metaphorical references can make a story about schizophrenia more engaging, relatable, and emotionally impactful, shedding light on the often intricate and

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<sup>35</sup>“Word salad” is a term used in the context of mental health and psychiatry to describe a symptom often associated with conditions like schizophrenia. It refers to a jumbled, incoherent, and disconnected arrangement of words and phrases that do not form a meaningful or logical sentence or conversation. People experiencing word salad may produce strings of words that don't make sense and are not organized in a coherent way.

challenging experiences of those living with the condition. These images and metaphorical references enable the readers to be privy to the multiplicity of lived experiences of the schizophrenic person. Although it may not necessarily generate direct demands for action and praxis, but it can certainly help in forming a shared collectivity of receptive people towards the schizophrenic person. While Valliappan's autobiography primarily explores the subjective experience of mental illness, it also touches on human rights considerations. The right to dignity, respect, and individualized care is fundamental for people with mental illnesses. Recognizing their experiences, supporting their autonomy, and respecting their rights to health and well-being are essential aspects of human rights in the context of mental health.

### **Reclaiming autonomy: Navigating disability, stigma, and human rights in Shivani**

#### ***Gupta's No Looking Back: A True Story***

Shivani Gupta is an accessibility consultant and author based in Delhi. Her autobiography *No Looking Back: A True Story* appeared in 2014 and it describes her journey as an orthopedically impaired woman as she navigates through Indian cities, particularly Delhi. It depicts the aftermath of an accident that leaves her using a wheelchair. It shows the times when the narrator experiences a loss of control, predictability, and trust in herself and her surroundings. Her disability is compounded by her inability to navigate certain aspects of the city's architecture that are not accommodating to people with disabilities. In the essay "Signifying Selves: Illness, Disability and Life Writing" (2017) Thomas Couser observes that the disabled writer takes charge of their life experiences in the process of reclaiming agency over their lives, which tend to revise generic ideas about what life-writing is, and their mode of representing the self, becomes a political and aesthetic act, a process of speaking for and speaking about disability [lived] life (Couser). Jerome Bickenbach is of the opinion that disability can be actually seen

as a fluid and continuous condition which has no boundaries. (Bickenbach). The narrating “I” claims the right to tell her story which also acts as a therapeutic exercise for her, but the narrating “I” draws attention to the various kinds of human rights violations meted out to her. Pramod K. Nayar observes that, “human rights depend on the assumption of a legal subject” (10). “This legal subject is self-determinate, meaningful and responsible” (Brugger quoted in Nayar 10). “The legal model of personhood consists of three foundational ideas: the capacity to bear a legal right, a biological body and a responsible subject” (Naffine quoted in Nayar 11). Anna Grear argues that ‘human rights need redirecting towards the embodied, vulnerable human being’ (3). Elizabeth Anker notes that ‘the dignified individual in possession of rights is imagined to inhabit an always already fully integrated and inviolable body: a body that is whole, autonomous, and self-enclosed’ (3). However, Anker writes, in order to generate the ‘dual conceits of human dignity and bodily integrity’, liberalism requires the ‘threat of bodies being violated, broken, and defilled’ thereby entailing that ‘human rights discourses and norms are ironically vindicated by inverse images of corporeal unmaking and abuse’ (4). Gupta begins her autobiography by recollecting the day of her accident, which leads to her being a wheelchair user, leaving her paralyzed in all four limbs. This significantly impacts her self-confidence, and she must adapt to an “alternate corporeality” to navigate through life in her wheelchair. She goes on to explain how her life takes a tumultuous turn after she becomes a wheelchair user, as she must contend with the ensuing stigma and the condescending gazes of others. Her condition threatens her sense of self because it forecloses her hopes- reminding her at the most basic level that she is not going to have any control over her life. The only constant then, seems to be deterioration and disruption. Gupta’s life takes a turn for the worse after her accident which poses serious challenges to her personhood which results in psychological distress. Since she becomes a wheelchair user following her accident, she chooses to regain control over her life and body. In the Prologue to her autobiography, she is caught in a web of conflicting

feelings of wanting to attend the college reunion party and at the same time, fleeing the city because of her disabling condition and partly because of the shame and stigma that would result from encountering her friends at the party. She writes, “the very thought of going out made me nervy and anxious-I was no longer used to such things, from the perch of a wheelchair” (Gupta 1). With the aid of her caregiver Ritu, she decides to attend the party. The venue- The Kingdom of Dreams in Gurgaon, appears ironic to her, because in her current condition, she is bereft of dreams. After reuniting with her old friends, she reflects on the events that unfolded in her life since the day of the farewell party she hosted many years ago. Her autobiography is structured into five sections, denoted as Book 1 through Book 5, with each section dedicated to a specific phase of her life that unfolds after her accident. The first section or first book, “Rebirth” describes the series of incidents immediately following her accident and ensuing paralysis, and the section begins with the narrator confined to a hospital bed, paralyzed, reminiscing about the events of the previous night. In her current anesthetized state, it appears as if she was dreaming all this while, still unaware of the reality of her condition. She remembers the farewell party she hosted at her residence after she quit her job at IHM. Thinking of this, she tries to move her feet but she cannot. She perceives her difficulty in moving due to a hangover from the previous night. It is only after her cousin, Laitik informs her about the accident does she faintly remember the events of the previous night. After the doctor’s examination, her lower body does not respond and she is diagnosed with a spinal injury. Firstly, she refuses to believe in the diagnosis because of her immobility and sheer helplessness that resulted from the condition. Soon she is shifted to the AIIMS for better avenues of treatment. The narrator explains that she was divested of her human status in the hospital:

The doctors put a rigid and uncomfortable collar around my neck before discharging me... I asked the doctor what he was going to do. He told me not to worry and that he was going to fix a skull traction. I did not know what that meant. Before I could ask more, he started shaving my head. (Gupta 15)

The narrator describes a medical procedure performed on her, involving the placement of a rigid and uncomfortable collar around her neck and the doctor's intent to perform a "skull traction." The narrator's experience in the medical setting raises questions about the right to autonomy and self-determination. The act of placing a collar around the narrator's neck and shaving her head without clear explanation or consent may be seen as a potential violation of her rights as a legal subject. The narrator's uncertainty and the lack of a clear explanation from the doctor may signify a lack of agency in this medical decision. The discomfort and uncertainty she experiences, as well as the invasive nature of the procedure, highlights the embodied aspect of her personhood. Anna Grear's argument that human rights should focus on the "embodied, vulnerable human being" resonates here, as the passage underscores the vulnerability of the narrator in a medical context. Elizabeth Anker's observation about the "dignified individual in possession of rights" inhabiting an autonomous and inviolable body becomes relevant. The narrator emphasizes the need for clarity in communication, informed consent, and the respect of an individual's choice and dignity in medical procedures, aligning with the broader discussions on human rights and legal personhood. In the life-narratives of Valliappan, Gupta, Monga and Pritam we see the destruction of the human [disabled or mentally ill] subject. Pramod K Nayar rightly notes that "this destruction is mapped out in the theme of the unmaking of bodies and the worlds in which the bodies are embedded" (4). Claiming humanity has been one of the important tenets of disability activism as it has been for other marginalized groups. Crystal Parikh puts it, "If human rights are the rights one has by virtue of being human, the definition of what it means to be human is of paramount concern" (8). She notes that adding disability to the domain of human rights can enlarge the notion of humanness. Disability life-writing has been instrumental in depicting the violation and debasement of the rights of the disabled person which auto-biographers like Gupta depict in her narrative. She describes that her personhood is violated at the hospital ward in the manner

she is made to undergo medical procedures without consent. The narrator continues to describe the ill-equipped interiors of the hospital, the nauseating smells of medicines and diseases looming large, the condition of the patients are reduced to the status of cattle and the dirty corridors and the callous medical attendants. She writes:

AIIMS shocked me. I lay on a stretcher for hours in a dirty and overcrowded corridor, along with so many others, in line to get admitted. Pained cries of people waiting to get medical assistance or a hospital bed filled my ears. Patients lay on the floor, not being strong enough to sit up- or perhaps just fed up of waiting to get a hospital room. Flies buzzed around the place and the obnoxiously strong odour of disinfectant was as effective against germs as it was in subduing all other smells. (Gupta 14)

The narrator seems to suggest the need for healthcare institutions to uphold and protect the human rights of patients, providing them with dignified, timely, and equitable medical care in clean and sanitary environments. Throughout her narrative, she describes the callous attitude of the doctors at the hospitals who are her primary caregivers, where they are mostly stupid, cruel and unconcerned. As she writes:

The doctor was whistling a melody from some old Bollywood movie while drilling my head. I was disturbed by this casual attitude. This was the end, I thought, the drill would go through my skull, through my brain, splitting my head open... (Gupta 16)

The facilities of the ICU are no less averse. The overpowering smells, and the callous attitudes of the nurses and doctors makes it one of her most harrowing experiences. During such times, her aunt and her sister Jiya and her father are at her beck and call following her mother's death. Confined to the hospital bed, she reflects on her childhood memories when her mother emphasized the significance of independence. Despite her mother's death, her family tends to her. Gupta is an introvert girl at school and her shyness is assumed to be a sign of snobbishness. She starts to idolize her elder sister Jiya in the absence of her mother- a sister who is responsible, conscientious and a living embodiment of her mother. The narrative moves back

and forth with the narrator remembering her bygone days and the brute realities of living in the present with her lower body paralyzed. She describes the extent to which she is reduced to an object. She writes:

The nurses were careless and rude, unconcerned about another's woman's privacy. To me, it felt like a violation of my body, but they seemed blind to this despite being women. It seemed unfair- even if they were doing me a favour by cleaning me when I couldn't do it for myself, as a patient surely, I deserved more respect? I decided to keep quiet about it. I was dependent on them and didn't want additional trouble for my family. (Gupta 28)

As a patient rendered invalid and confined to a hospital bed, the narrator becomes dependent on the hospital staff and nurses, and she experiences a sense of being dehumanized, as if she's treated as an object put on display. She notes:

They continued to discuss me while I stared up at them, feeling like an object on display that these young doctors would be learning from and experimenting on. (Gupta 28)

Here, Gupta cites an instance where her humanity and human dignity are violated when her body is unmade and inverted. Despite being a patient who is dependent on their assistance, the narrator feels that her body's privacy is violated. The lack of respect for her autonomy and dignity, despite her vulnerable state, raises concerns about the violation of her rights. The narrator's decision to keep quiet about it due to dependency on the staff and not wanting to cause trouble for her family underscores the power dynamics at play, where the patient feels compelled to endure mistreatment out of fear or vulnerability. The narrator's description of feeling like an "object on display" for young doctors to learn from and experiment on suggests a lack of agency and respect for the narrator's autonomy. This perception of being treated as an object rather than a person with rights further emphasizes the violation of the narrator's dignity. Through these instances, Gupta seems to raise questions about the ethical treatment of individuals in vulnerable situations and the need for a more rights-based approach to healthcare. Gupta writes that she suddenly learns about the importance of the sensation of



touch, and its importance. She has taken it for granted all her life, it seems that she does not have it anymore. In spite of this, she is hopeful of recovering soon and eagerly anticipates leaving the hospital as soon as she can. Her family is busy in absorbing the doctor's information without really understanding the prognosis. The doctors have declared that she wouldn't be able to progress much and would remain a "vegetable". She becomes extremely conscious of her appearance and is astonished by the changes in her physical appearance after the accident. The positive consequence of her dependency on her family and caregivers is that she becomes an extrovert and gains confidence. She describes:

The upside of the painful experience was that I learnt not to depend on anyone except myself and finally emerged from my self-conscious shell. I become an extrovert and gained confidence in myself, as I knew that I had to do it all on my own. There was no one I could hide behind anymore. (Gupta 31)

The narrator further describes the condition of the medical establishments in the 1990s when there was not much information about spinal injuries. She describes her current condition as such:

I felt as if I had been reduced to just a human body lying on a bed- mindless, thoughtless, emotionless. I had tubes coming out of my nose and bladder, tubes going into my arm, from my head hung bricks, I never changed my position. I was paralyzed shoulder downwards... (Gupta 35)

She is rendered as an 'object body' which is transformed into an excess, grotesque and ugly spectacle. The description of feeling reduced to "just a human body lying on a bed" implies a loss of personhood and individuality. The narrator uses terms like "mindless, thoughtless, emotionless" which points to her dehumanizing experience, emphasizing a lack of recognition of the patient's psychological and emotional well-being. The mention of various tubes and the physical conditions the narrator is subjected to, such as being paralyzed shoulder downwards and unable to change position, adds to the sense of vulnerability and powerlessness. The violation of bodily autonomy is evident in the invasive medical procedures described. The

patient's inability to move or change position may contribute to a feeling of helplessness and loss of control over one's own body. So, Gupta describes the space of the hospital during the 1990s which becomes a site of violent and brutal expulsion where the individual is transformed into a stranger and is unrecognizable. The first thing that she recounts after her transfer to Dr Chahal's clinic is that she has to undergo a surgery in which her skull traction is removed- a sign which indicated a ray of hope towards recovery. She is initially hesitant to face the world in a wheelchair, and she decides to stay back in the hospital for another month. Soon after, she undertakes her journey as a wheelchair user to Pune for rehabilitation. After reaching the rehabilitation center in Pune, she is shocked by the rigorous physiotherapy sessions she undergoes because of which she suffers from bouts of depression. It is only after she meets other wheelchair users at the institute, she is able to comprehend the permanence of her situation. This is her first experience of living with disability. She writes:

I had never thought about disability before my accident. Neither had I known anyone who was disabled. Disability had meant social work sessions at school and a feel-good factor from having assisted a disabled person in crossing the road. Disabled for me, until now, had been 'them'. But now... (Gupta 45)

Her self-esteem is hurt because of the prejudiced remarks and sarcastic comments from people. The second book, "Discovering the Spirit," explores how the narrator manages the complex challenges posed by her disabling condition. After her return from Pune, she writes that... "the familiar signposts of her hitherto independent existence had vanished" (Gupta 48) as she is wheelchair bound and certain places become inaccessible. Most of the buildings in Delhi are planned in a way that is not conducive for the disabled person (53). For instance, her mother's second-floor apartment is not accessible to her due to which she has to be shifted to her grandparents' place. She longs for a life of seclusion. She has to be dependent on Putul, her caregiver. Soon, she grows increasingly irritable because her privacy is compromised in the

company of her caregiver. Being in the presence of the caregiver reduced the family's burden, but it also resulted in a compromise of her privacy. She writes:

Having a carer also meant goodbye to the privacy that is usually important to maintain one's sanity. Life with a carer wasn't just a compromise on physical privacy but also emotional privacy- there is little space left for your deeper thoughts with a person constantly with you. Despite everything, however, I also realized that a carer was definitely less demanding on the mental independence when compared to family – my carer was the person because of whom I was going to stop being dependent on my relatives and gain enough independence to do whatever little I could. (Gupta 52)

Prior to her accident, she envisions disability as a deficit. After her accident and the resultant paralysis, she tries her best to dispel the images of helplessness that comes with it. She does not like her dependence on the manual wheelchair because it signified immobility and helplessness. Although the disabled hostile buildings of the city prevented her from entering certain locations, she finds solace in performing little chores for her grandparents which gives her a sense of accomplishment. She recalls her fondness for painting during college days and now her incapacity to hold paintbrushes. She loathes herself because she is unable to hold a paintbrush or write properly even a year after her accident. Despite her inability to hold a paintbrush, she uses it as an exercise to facilitate the mobility of her hands. The first instance of self-confidence is instilled in her when her neighbour suggests her to sell hand-made greeting cards at the college fair. Despite the physical limitations, the narrator demonstrates agency by using painting and preparing hand-made greeting cards as an exercise to improve the mobility of her hands. This reflects her determination and resilience in trying to regain some control over her physical capabilities. Gupta repeatedly stresses on how the city's architecture exacerbates her problems of navigating the city as an orthopedically disabled person. Dressing up for the occasion of visiting the fair is accompanied by feelings of self-doubt, because her disability had affected her appearance and she feels she can no longer connect to her femininity. At the fair, she is amazed by a lot of positive responses she receives and no one seems to be

bothered about her disability. She also writes that the governmental programmes for people with disabilities revolves around concessions and reservation instead of creating an enabling environment. In these circumstances, painting becomes her only means of self-expression and reclaiming a sense of control over her life. The acceptance of her hand-made cards at the fair is one of the first instances of her inclusion into the society. The will to become self-reliant instills new hopes in her.

Painting brought some meaning back to my life and helped in healing my self-worth. The hurt I felt every time people sympathized with me was mitigated when someone appreciated my work, my talent and my ability. Besides, painting gave me an identity. Often, one is judged by what one does. And painting gave me an answer to the question ‘What do you do?’ I was a budding artist! (Gupta 69)

Despite the various challenges faced by the narrator because of her disabling condition, there are several modes of self-expression such as painting and writing through which she attempts to gain control over her life and body. Gupta’s engagement with painting becomes a source of meaning in her life and contributes to the healing of her self-worth. This suggests a proactive effort on the narrator’s part to address the emotional and psychological aspects of her well-being, demonstrating resilience and self-reliance. By identifying herself as a “budding artist,” Gupta not only establishes a personal identity but also positions herself as an active and evolving contributor to the artistic community. This contributes to her autonomy and self-reliance as she shapes her identity beyond the constraints of societal expectations or limitations imposed by her disability. The narrator decides to work in the rehabilitation sector for empowering the disabled upon the insistence of her family counsellor- Vikram Dutt. She is not keen on continuing with her paintings despite the laurels achieved because of the sensationalization of the job by the media by which her creative work becomes indistinguishable from her disability. Dutt advises her to take up a job as a peer counsellor at the Indian Spinal Injuries Centre prior to which there will be a two-month training programme

in the UK. After reaching the UK and on her way to Duke of Cornwall Spinal Treatment Centre, the narrator observes vital differences in the ways in which the disabled are treated in India and the UK. The first thing she observes is the disabled-friendly architecture in the UK, which is not commonly seen in India. The people in the UK have more accommodating attitudes towards individuals with disabilities, and they are not treated as objects of ridicule. At the Spinal Centre, there are several self-reliant individuals with disabilities. She writes:

The most important learning for me from this trip was the realization that disability was not the end of the road; rather, it was just an obstacle to be overcome through rehabilitation. It was in Salisbury that I understood the true meaning of rehabilitation. I also understood disability a little better- that being disabled wasn't a big deal. All the patients at the rehabilitation center projected an attitude of being regular people who happened to be using a wheelchair. There was not an ounce of sympathy or charity that their demeanour invited. It was amazing to be there- an absolute eye-opener.

(Gupta 76-77)

In the UK, the disabled persons have more mobility and access compared to India. When she returns from the UK, she decides to work towards improving accessibility for the disabled. This acknowledgement of the “sense of agency” and action is one of the first steps she takes in speaking against the inequalities in accessibility and support for disabled individuals in India. Shortly after, she joins the Indian Spinal Injuries Centre in Delhi. She is allotted a quarter in the campus since commuting will not be a feasible option. But the staff quarters are not adequately planned to accommodate a disabled person. As a result, she begins using her lightweight manual wheelchair she brought from the UK, which significantly eases her mobility. Due to the absence of students at the Indian Spinal Injuries Center, she was unable to engage in peer counselling. As a result, she starts compiling fact-sheets on various aspects of spinal injury, instead. When there are a few students at the center, she imparts training to them in four different ways: first, she introduces them to the concept of spinal injury, secondly, she educates them about navigating their everyday lives, third, she provides real-life examples from

the lives of people living with disabilities and fourth, she addresses issues relating to communicating with their families (Gupta 86-87). She continues to navigate the unfriendly streets of Delhi- at educational institutions, offices and multiplexes. The narrator acknowledges that changes in the architectural structures have still not been implemented and the planning of the urban city do not attend to the needs of the disabled persons. She then describes the bond she develops with Vikas, who is studying to be an occupational therapist. Soon, Vikas and Shivani develop a strong bond. He listens attentively to her life story, and it becomes clear that Vikas is more empathetic than her prejudiced friends. The most significant thing she learns from Vikas is “to accept people as they are and to appreciate what they did” (Gupta 109) which is evident in his attitude of accepting her as a disabled person. Soon enough, she feels that “her disability no longer mattered to her” (Gupta 110). Despite the differences in temperaments and natures, their bond is further strengthened. In the third book “Learning to Fly”, she shifts her point of view from the personal details of her life to describe the various measures she undertakes towards improving access for disabled persons. She attends a workshop hosted by the United Nations Economic and Social Commission for Asia and the Pacific in Bangkok which trains the participants in ‘Non-Handicapping Environments for the Disabled and the Elderly’. After her training sessions, her anger is directed towards the planning and decision-making bodies in India which still cannot provide an accessible environment to its disabled citizens which is a violation of their human-rights. Since then, her priorities shift and she starts working towards improving the prospects for disabled persons. With the assistance of Vikas, they come up with the NGO Access, which is “to coordinate the first ever awareness-raising project on the subject in India” (Gupta 122). In due time, they come up with a book called ‘Planning a Barrier Free Environment’, renamed as ‘The Green Book’ which is used for training purposes and as a technical guide for architects and civil engineers from across the country for getting specifications for building barrier free buildings (Gupta 123). Following

the guidelines in the book, many access audits are conducted across the country which identifies barriers in an environment and works towards constructing more accessible infrastructure. At this juncture, Vikas receives an invitation for training as an occupational therapist in the UK followed by a trip to Paris and Brussels. While navigating the streets of Paris, the narrator is disturbed by the ill planning and poor design of public spaces which created problems for her as a disabled traveller. Despite the place being signposted as accessible, it is due to the “architects, designers and engineers’ distorted understanding of accessibility”, that such places are rendered unusable for her (Gupta 137-138). Similarly, the “cobblestone streets” of Brussels proves to be difficult for her to navigate. When she returns to India, the narrator quits her job as a peer counsellor at the spinal centre and joins as a full-time student at a private university. Her own flat is given out on rent and she moves to an accommodation closer to the university campus. Despite the inaccessible environments of the campus, she manages her incontinence. Meanwhile, Vikas enrolls in the PG programme for creating accessible environments and joins as an occupational therapist at one of the hospitals in the UK soon after. After the loan is sanctioned by the National Handicap Finance and Development Corporation, the narrator sets out to enroll in the PG programme which would equip her with the knowledge required for mainstreaming disabled persons in India. While the course is primarily designed for the British systems and laws related to creating inclusive environments for disabled individuals, including training in public transport, housing, communication requirements, and accessibility laws, it equips her to contribute to the development of an inclusive environment in India. The formal training in the field of accessibility enables Vikas and Shivani to open up “AccessAbility”- the first inclusive professional organization which would cater towards meeting the needs of the disabled. At her workplace, however, she faces discrimination in subtle ways, where her disability is made an issue and her abilities are undermined. The section ends with their organization AccessAbility

reaching out to its national and international audience. The fourth book, “Gaining Acceptance,” is filled with personal details from her life, chronicling the development of Vikas and Shivani’s relationship, which ultimately leads to their marriage. It also highlights how Vikas’ family comes to accept Shivani, despite their initial reservations. Despite oppositions from various quarters, Shivani and Vikas get married. After their marriage, their family plans to go on a weekend trip to Manali. On the way to their destination, the car meets with a terrible accident which eventually changes the course of events in the narrator’s life. The next thing the narrator remembers is that she wakes up to the news of the death of Vikas in the hospital. The section ends with the narrator expounding that due to the ill-equipped facilities of the hospital and the management and the negligence of the medics, Vikas succumbed to his injuries. The concluding section of the book, titled “Another Journey,” begins with Shivani working as an accessibility consultant for “AccessAbility,” fulfilling Vikas’s dream. Her commitment to this dream appears to be the sole means of escaping the emptiness that followed her husband’s demise. Vikas’s death prompts her to contemplate philosophical questions related to the essence of love, life, detachment, and the art of letting go. Gupta writes:

It became easier for me to see my life objectively, with a degree of detachment. It was not hard for me to meditate as the lack of any desire had erased all the clutter from my mind. I came to the realization that, in the midst of all that was fleeting, a higher search and a deeper connection with oneself were the only things that held any real meaning. I felt calm and cleansed, like a slate that has been wiped clean. (Gupta 230)

The narrator describes a significant shift in her perspective and outlook on life after Vikas’ death, with a newfound focus on inner growth, detachment from worldly desires, and a deeper connection with oneself. She comes to the realization that love is not about “possessing but letting go” (Gupta 231). With the erasure of Vikas’ physical form from her life, she feels the urge to continue with his dream all the more strongly. In the process, she also understands that



death gave her the meaning of life. Vikas' physical presence in her life had "...had made me complacent, whereas sorrows made me exert myself to improve further" (Gupta 231) and that "love as a reality that transcends physical form-by living a life he wanted, and dreamt of, for me" (Gupta 235). It is during these times, she feels the urge to author her story, to give a lie to assumptions on her disability. While she writes her life narrative, she imagines the voice of Vikas in her head as her sternest critic. The presence of Vikas in her thoughts while writing allows the narrator to maintain an emotional connection with him. It is as if he is still with her, guiding and influencing her thoughts, which is comforting and reassuring. Writing her life has been reassuring and therapeutic. As she writes in the autobiography:

What had started as scribbles in old registers became the most revitalizing experience of my life. Not only did the journey of writing my book give me a chance to relieve my entire life but it also gave me the opportunity to make sense of it all and let go of the negativity that blocked the clean flow of understanding. It gave me the courage to accept what fate had meted out to me and be strong enough to carry on. (Gupta 238)

Writing her autobiography becomes a means for the narrator to make sense of her life, heal, let go of negativity, and find the strength to move forward. It underscores the importance of storytelling as a tool for personal growth and empowerment. The narrative ends with the epilogue describing the numerous measures undertaken by the narrator towards improving access and mobility for people with disabilities. Shivani Gupta's narrative stresses that telling our life stories make us vulnerable but such stories need to be told to describe the lived experiences and challenges faced by individuals with disabilities in the context of human rights. These stories are essential for raising awareness, advocating for rights, shaping policy, challenging stigmas, and holding individuals and institutions accountable for their treatment of people with disabilities. To conclude this section on Gupta's autobiography, *No Looking Back: A True Story* predicated its conceptualization of rights on vulnerability- the rights of the disabled person. Although the narrator of the text possesses rights in the abstract, many of them

such as right to speech, right to movement and right to privacy, and to proper health care are violated in the autobiography. One of the ways, I maintain, is the very act of writing, as Gupta notes- the transformative power of telling her story will help her connect to her husband. Writing becomes a moment of righting herself from the human rights violations meted out to her and problematizing the ableist notions on writing and creativity by asserting that there is no single, normative way to engage in creative expression and that their unique experiences and perspectives should be valued and included in the creative discourse. She embraces her wheelchair bound inhibited and insecure self and explore the range of possibilities implicit in her anomalous embodied self.

### **Writing the empowered self: Rights, narrative identity and self-discovery in Sarmistha**

#### ***Pritam's Sun on My Face***

Sarmistha Pritam's *Atmakatha* was originally published in Assamese in 2007 and it is translated into English as *Sun on my Face* by Prafulla Kotoky in 2014. Pritam has also authored *Antaheen*, (2014) a biographical account of the Australian motivational speaker living with tetra-amelia syndrome (the absence of arms and legs). Chitra Harshvardhan in her essay "Translation as Social Action: The counter-discourse on the literary representation of disability" (2019) writes that the act of 'translation' is an instrument that fosters cultural alterity by positing an alternative aesthetics (37). Harshvardhan's emphasis on translation fostering alternative aesthetics aligns with Pritam's efforts to present disability in a different light. By sharing her personal experiences and emotions, Pritam introduces an alternative aesthetic that contrasts with the reductive and stigmatizing views of disability in society. Pritam's autobiography can be seen as a form of self-translation, where she reinterprets her own experiences and self-presentation within the context of societal norms. Her narrative reframes the concept of

disability, moving it away from reductionist views to a more nuanced and holistic representation. This aligns with Harshvardhan's idea of translation as an act that transforms and broadens cultural understanding. In his essay “Disability and Autobiography: Enabling Discourse” (1998), G. Thomas Couser suggests that the crux of the study of autobiography and disability has to do with the matters of mediation: the conventions of the genre of autobiographical writing and the experience of disability (1). To him, the liberating potential of the autobiography lies in its self-representation which attempts to problematize societal norms and perceptions. In her autobiography, Sarmistha Pritam writes [right] herself into an ableist society. Pritam describes “a social setting in which parochial social understandings of impairment and a standardized understanding of beauty, health, fitness and competence lead people to view her disability in reductive ways resulting in further stigmatization and vilification” (Purkayastha 46). Sarmistha Pritam writes in her autobiography:

...life is an endless journey overwhelmed with passion, a ceaseless pursuit. Sometimes I feel it is an unrealized dream, an abstract longing. Someone has said, “Life is a tale of painful facts”. I believe that the ‘painful facts’ keep life vibrant for the more the fire of agony burns, the more the power of man’s mind and soul grows. On the whole, life is indeed beautiful with its volatile accompaniments of happiness and sorrow, success and failure, love and passion. (103)

Pritam perceives her disability as an ongoing journey, where she discovers new opportunities each day. She underscores that the pain and hardships in her life have played a vital role in shaping her autobiography. In the penultimate section of her autobiography, she recounts an encounter with Ripunjoy Tamuli, who is living with a life-limiting disease and visits her with his parents. Ripunjoy demonstrates remarkable patience and perseverance, even compiling a book of poems and pictures before losing his ability to hold a pen. It is only after Ripunjoy’s father shares some information from the internet that the narrator learns about the cause of her disability for the first time- Spinal Muscular Dystrophy- “a disorder caused when the nervous

system and the motor neurons connected with the spinal cord and the brain stem are affected. The tendons that keep the walking and sitting and swaying of the head active gradually become weak and ultimately exhausted” (Pritam 180). Realizing the incurable nature of her disability, she persists in her writing. In the early chapters of the text, the narrator has a conversation with birds, who possess the ability to fly, in contrast to the protagonist who is dealing with spinal muscular dystrophy, a condition that affects her mobility. She writes:

The birds, too, took wing, each with a song on its beak. Their sports and antics in the mud and dust beckoned me. The little ragdolls awaited me...My legs, slugging slowly ahead, wished they would fly, only if they could. (Pritam 1)

Pritam consistently emphasizes that within her vivid and boundless imagination, which grants her free access to the world she envisions, she never perceives her physical disability as a limitation or deficiency. She shares childhood stories of playing games that did not demand extensive physical movements. Pritam highlights the various ways in which her culture associates disability with impaired minds, bodies, and moral deterioration. Pritam recollects the memories of her childhood from collecting the dew-drenched “sewali” flowers to the licking of black berries, she recalls moments when her parents persuade her to move quickly as she grows weary after covering a short distance. At that time, her family was unaware about the consequences of her disability and the parents often attribute her inability to her sheer laziness and unwillingness. Due to her slow pace and the “ceaseless flow of traffic”, her parents dissuade her from crossing the streets. While her friends mostly engage in games that require physical movements, she sits back and observes the clouds and harbours thoughts of becoming a bird (Pritam 5). Most of her experiences of childhood are gathered in the midst of natural surroundings. In *Contours of Ableism: The Production of Disability and Aabledness*, Fiona Campbell (2009) writes that ableism is not simply a prejudice or discrimination against disabled people, but rather a system of oppression that creates and maintains disability.

Campbell argues that ableism is embedded in our social, cultural, and economic institutions, and that it shapes the way we understand and treat disabled people (4-5). Building on Sara Ahmed's (2006) articulation of orientation as "being about facing certain objects...that help us find our way," (1), Campbell describes this disorientation ontologically as, "the lived experience of facing at least two directions: towards a home that has been lost...and to a place that is not yet home" (194). Pritam's autobiography explores the tension between the lost home, representing societal norms and ableist views, and the place that is not yet home, symbolizing Pritam's quest for acceptance and understanding, resonating with the disorientation experienced by disabled individuals in the face of societal attitudes. Pritam's exposure to the sights of nature, or the mobility of the birds and others, are productive ways of knowing and imagining the possibilities that exist in the world. Within the confines of her house, the objects which catch her attention and with which she develops a bond include the swing and the paddy basket. She describes her bonding with the house-help whom she respectfully calls Roti *baidew* (*baidew* meaning elder sister) and plays *cheng guti*<sup>36</sup> with her. She also develops a bond with Mithun, the maid's son who stutters. For Pritam, suffering accruing from her disability proves to be the epicenter of all her sufferings. During her childhood days, an attack of typhoid possesses weakens her already fragile immune system and its effects linger long after the illness subsides. After a regular visit to a local hospital, she is advised a regular massage with an oil along with a few physical exercises. Her keen desire to dance did not materialize because of her weak grip and frail control over her muscles. Pritam desires to climb the stairs which causes her mother much anxiety. In an instance from the text, Pritam expresses her unease over using a person's deformity to provoke laughter after witnessing the dwarfs performing in the circus.

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<sup>36</sup> A folk-game played by children in Assam.

A part of her recollections from childhood also includes the memory of her ailing grandfather who had lost his mental balance in the days leading upto his death. Pritam's autobiographical narrative problematizes the commonly held notions of disability in Assamese culture as markers of loss and deficiency, while advocating for the rights of the disabled person in a small town of Assam. At the Phulaguri primary school, where Pritam is initially admitted, the other children often pass comments and stare at her for her unsteady steps and the overtly sympathetic attitude of the teachers coupled with pity owing to her disability, made her withdraw further into herself. She also recalls the time when her father used to tell her stories having open endings, a tactic he employs after she grows weary of listening to Assamese folk tales. Her father's mind is a "treasure house of fairy tales" (Pritam 30). He does not merely restrict himself to Assamese folk stories but narrated stories from the Panchatantra, Aesop's fables, Gulliver's Travels and Anderson's tales for children. For long years during her childhood days, she does not exhibit any symptoms of her future impediment. Although she visits a few doctors, none of them make a clear diagnosis and pass it off as signs of physical weakness. Even her parents are unsure about how and when her ailment started, as she writes:

My parents did not exactly know when my ailment started. They thought it might be from my birth but they were not sure. I was born on December 18, 1985...They say I did not cry as soon as I was born, but was quiet...This made me curious. It's natural for a baby to cry at birth. But why did I not cry? Perhaps that was an indication of my ailment, a warning of my future impediment. (Pritam 33)

She recalls the moment when a Guwahati based doctor diagnoses her with spinal muscular atrophy and recommends a series of treatment regimes. After a distant cousin of hers recommends a hospital at Sibsagar where physical deformity could be 'cured' through acupuncture, she is taken to the clinic and is subjected to the same treatment. When the treatment fails to produce any desirable results according to her parents, she grows feeble. After her parents consult a doctor at Assam Medical College in Dibrugarh, they are informed that the

treatment she had received at the M/S Sapalla Polyclinic in Sibsagar was incorrect. It is revealed that she has a spinal deformity, and the treatment she received in Sibsagar was intended for polio. Following the recommendation of the consulting physician at Dibrugarh, the family sets off to the International Institute of Advanced Homeopathy in Calcutta. However, their visit to the doctors turns out to be a futile exercise as she loses her ability to walk after they return from Calcutta before she is admitted to high school. These instances describe the violation of the rights of the disabled and underscore the importance of upholding the human rights of individuals with disabilities, including the right to accurate healthcare, the right to mobility, and the right to education. The narrator also emphasizes the need for awareness and advocacy to ensure that these rights are recognized and upheld, especially for people with disabilities who may face specific challenges and vulnerabilities. Due to Pritam's mobility impairment, activities requiring movement of the leg muscles become difficult for her and she feels pained at the thought of being restricted at one place. Her father brings her a harmonium to teach her singing which is in part her mother's desire, which again fails to produce any intended results. She describes how her native place Phulaguri comes into prominence with the Phulaguri scuffle of 1857 when the landless peasants inspired by the 1857 revolt, spark a protest in response to their exploitation. Her place is named so by an Ahom king who named it Phulaguri- meaning an abode of flowers, since the place abounds in creepers and flowers. Due to her mobility impediment, she had the opportunity to spend more time listening to her father's stories. Most of her time she reads or communicates with her pets in "the language of endearing touch" (Pritam 59). She describes how her other senses become receptive due to her disability. After attaining puberty, she is not confined to a private room as is the custom with able-bodied girls, but she is given a folding bed beside her sister's bed. The rituals for her ended on the fifth day unlike the customary seven-day practices. Her life worsens when her father is diagnosed with thyroid cancer from which he eventually recovers, but most of her father's income is spent

on his and his daughter's treatment. To make ends meet, Pritam's brother begins to run a pharmacy in the vicinity. She then recalls an incident when she meets with an accident on her way to visit the pharmacy with her father. Due to her already weak muscle joints, she loses balance frequently as a consequence of which she has to depend on her family and relatives to be her caregiver which causes her anxiety and shame. She describes the customs, food habits, games and rituals of the Assamese in detail along with expressing her regret in not being able to actively participate in either of those because of her impairment. Pritam also describes her habit of recording her experiences in a diary. Inspired by Anne Frank, the diary is Pritam's constant companion during moments of distress and agony. Due to the negative comments made by people, she grows increasingly irritated over her affliction, withdrawing into herself, and jots down her experiences of living with pain in her diary. She writes of her travails during her high school days:

... I was losing my ability to walk. Walking by holding on to outside support also became difficult. One day father posted in our backyard two pieces of bamboo high enough to reach up to my waist. He then tied a piece of bamboo connecting the two. For some days, my sister took me out in the morning to practice walking by holding on to the piece of the bamboo. I walked a few steps very slowly but I felt like I was faltering. That was for me a very painful experience, a terrible fight. (Pritam 44)

The narrow social expectations about a specific physical standard leads them to perceive her disability as an aberration. People have gone as far as suggesting ways to cure her disability by visiting an astrologer, fortune teller or a godman. She recounts an incident from her superstitious village where a woman's frenzy is mistaken for possession by a goddess. There are other incidents which the narrator describes in her autobiography such as the attempts made by her kin to cure her impairment by bringing in a masseur or a devote who claimed to be a worshipper of Kali. Such instances suggest that individuals with disabilities may face human rights violations when their conditions are subjected to superstitious practices, stigmatization,



misinterpretation, and ineffective or potentially harmful treatments. These violations can impede their right to quality healthcare, their right to be free from discrimination, and their right to be treated with dignity and respect. At one point in the narrative, she describes the inaccessible environments for the disabled which makes it difficult for her to navigate its terrains smoothly. It is only after she is involved in a romantic companionship with Ritu, she finds a new horizon beckoning her. Kanchan Barua's *Asimat Jar Heral Seema* (He who lost his limit in the infinite) leaves an indelible imprint in her mind which further leads her to read many books on Assamese literature which provides solace during moments of distress. Giribala of "Datal Hatir Weyekhowa Howda", Menoka of "Antarip" and Binapani of "Ayananta" exert tremendous influence on her. It becomes a habit of hers to note down quotes which stays with her in different ways. She does not like the idea of exercising to relax and activate her muscles which her family wants. She wants to become a teacher but the act of navigating in the disabled unfriendly architecture made her rethink her choices. Apart from books, her Bardeuta's (father's elder brother) words of wisdom provides the much-needed solace. As her high school exams draws near, she feels a slight unease as she has to write fast- an act which requires her to exert her whole-body strength. In the narrative, she admits that since her situation cannot be improved, it is better to accept it as it is. She notes:

...I remonstrated with God for dooming me to suffer one mishap after another. Later, however, I realized that it was my destiny which cannot be countered either by prayer or protest... This awareness helped me overcome my agony of body and mind. I believed that in certain situations of life there is no alternative to accepting them as best as one could. Pritam 77)

Despite various digs at her disability and subjectivity, she does not give in. Kelly Oliver holds the view that "conditions of oppression debase and destroy the subjectivity by othering the individual" (2). She writes:

Being othered, oppressed, subordinated, or tortured affects a person at the level of her subjectivity, her sense of herself as a subject and agent. Oppression and subordination

render individuals or groups of people as other by objectifying them. Objectification undermines subjectivity: to put it simply objects are not subjects. Through the process of bearing witness to oppression and subordination, those othered can begin to repair damaged subjectivity by taking up position as speaking subjects. (Oliver 7)

However, she demonstrates remarkable courage and patience in the face of stigmatic remarks. She often contemplates the meaning of life when left alone. She reads Camus who suggests that despite the meaninglessness of life, one can imbue it with one's actions, profoundly impacts her. The story of the impaired woman named Hana Yamahata in Homen Borgohain's *Jeevanar Sadhana* inspires her. After completing her matriculation examination, she is admitted to Raha Higher Secondary School where she faces ordeals similar to the ones, she faced at her previous schools concerning movements in and around the campus, note taking in which she is assisted by a friend. Due to a friend's insistence, she joins a Poetry Club but she has this recurring fear of public speaking which she eventually overcomes with practice. Engaging in activities of the Poetry and the Nature Club helps her in alleviating her pain. Soon after, she begins sending write ups to *Dainik Asom* (a regional daily) and *Mukuta* (a children's magazine) in which they are published. She writes that it is with her active participation in the meetings and activities of the Poetry Club which "activated her pen" (Pritam 103). She reads about Stephen Hawking and finds his words of wisdom reflecting her sentiment. Her father opposes accepting governmental assistance for her disability. She comes across an article in the newspaper about Ritam Deka, a person living with a severe impairment, excels in his exams and this inspires her. She has distinct memories of a distant uncle who is daily wage-earner from the Tiwa community who finds happiness with the little things in life. During her higher secondary examination, she is demoralized over the fact that she cannot complete her paper as her hands were growing stiff and immobile while writing. During moments of anxiety, the times she spends in the company of nature along the banks of the Kolong "crept into the depth of her heart" (Pritam 114). In her hometown, the inclusion of differently abled candidates in

educational institutions has not been put into practice. Consequently, she is unable to participate in undergraduate examinations as a private candidate. She regrets the absence of a disabled friendly environment across educational institutions and workplaces in Assam. She writes:

I head of some legal provision for the physically handicapped. But I do not know how far they have been implemented. No one has the right to deprive a person of the facilities for living a worthy life. In foreign lands, there are measures thanks to which no man suffers deprivation on account of physical disability. Even in going to public places, I am told such a person does not face any inconvenience. There is the provision of wheelchair whenever needed. There is provision for the physically disabled for getting a job on the basis of their qualification, and accordingly, it is the bounden duty of the government to make provision for a wheelchair at school and colleges. But in our country, nobody is aware about these privileges. (Pritam 115)

Pritam is critical about the policies of the Assam government which is yet to implement policies for a disabled friendly environment in the region. As in Shivani Gupta's autobiography, Pritam also enumerates the unaccommodating attitude of the city planners, who construct certain infrastructure that do not address the needs of able-bodied persons. Although the Person with Disabilities Act was passed in 1996, the implementation of the provisions of the Act remains a distant dream in many regions across the country. She is regretful of the government's sluggish approach to policy implementation as she writes:

...many states of our country have not so far implemented the Act and even in the few where it has come into force, the provisions have not been properly affected. Assam is said to be lagging behind in this matter. Also, because of social considerations, many a victims of physical disability suffer from inferiority complex. I cannot foresee when social discrimination, towards the disabled will end, when will our attitude to disabled persons change. But we must go ahead with courage and determination ignoring the obstacles on our way. (Pritam 115)

After reaching a certain age, the narrator is compelled to use a wheelchair as she finds it uncomfortable being carried around by her family members. The arrival of the wheelchair

facilitates her mobility to a certain extent but the handicap lies in the architecture of the Assam type house, as she notes:

My difficulty was exacerbated by the fact that in our Assam type house, every room had a raised threshold, and a narrow door passage. These problems had not been foreseen. As a result, for some time after it arrived the wheelchair remained unused.

(Pritam 116)

Soon, the doors are recast and provisions are made to ease her mobility within the confines of the house. In her autobiography, she does embrace her condition and advocates for a more inclusive environment specifically for people with a mobility impairment. She recounts an incident of certain people with mental differences from her village- Hira the lunatic, who talks to trees and blabbers endlessly and a mad beggar who considers himself to be the President of India, a man who believes a snail is stuck to his clothes and another girl who is progressing physically but her mind is regressing. For Pritam, the sufferings of the mentally disabled is more than the ones with physical disabilities (Pritam 121). An important turning point in her life comes when she begins her correspondences to a young man, her pen-pal, who inspires her to write personal essays, letters and columns. In one of his letters to Pritam, he describes an account of a blind boy who has a keen desire to learn and study and has a dream of going to Oxford. Despite the family's poverty, they set out for Oxford and as the family describes the places and people they encounter to him, the boy perceives them through his sense perceptions. He eventually publishes an account of his experiences in the form of an autobiography, *Oxford in Winter*. Besides sending a copy of his autobiography to Pritam, he sends her accounts of other persons with disabilities and their inspiring stories. Likewise, they share their life stories with each other. The young man seeks her companionship but Pritam is hesitant to reciprocate. With the coming of this young man into her life, she becomes "a moving stream from a stagnant pond" (Pritam 134). It also fosters her love of writing and through the exchanges of letters,

they travel to distant places without physically journeying to the place. Thus, given the opportunities for greater freedom, the act of writing is often seen as an “ability” and a mode of exercising agency. Although the concept of agency is rooted in a variety of different things, the basic understanding of the term implies the ability of human being to make choices and act on them. This urge to write enables her to send write ups to regional dailies and magazines. She also writes about the customs of her community and the problems of poverty, social discrimination which beset the villagers. The act of writing and sharing her perspectives, concerns, experiences in regional dailies and magazines and about the customs of her community reflects the exercise of the fundamental human right to freedom of expression. This right allows individuals to freely express their opinions, share information, and contribute to public discourse. Since she is a wheelchair user, her interaction with the villagers grows more and more restricted. But certain words of motivation from the young man kindles in her a spirit of self-confidence. He writes:

Never must say that you're crippled, motionless, immobile. Never say you would not get anything. You'll get everything. Not with my support. But with your regenerated self-respect, unblemished energy, and wealth of your heart. I'm only a third hand for your life. When you're tired, I shall pick you up. (Pritam 138)

Although the lines quoted above acknowledge the role of external support but Pritam frames it as a secondary resource rather than the primary source of empowerment. It conveys the idea that while support from others can be valuable, one's primary source of strength and motivation should come from within. These are like an “elixir”, an “enlivening mantra” which boosts her morale during difficult times (Pritam 138). She comes across works of literature such as Nicolai Ostrovsky's *How the Steel was Tempered* which narrates the tale of Pavel Korsagin, treading through the abject poverty and hard labour during his childhood and adolescent years, suffering bodily injury during the civil war. This man embarks on a task of nation building, following his multiple disabilities from the war. His dream of writing a novel is materialized, with his

indomitable will. This little story works as a tonic for her to continue her creative endeavours. In the course of her narrative, she writes that “I should rather be thankful to my disease. It confined me to bed and gave me ample time for reading” (Pritam 147). In the autobiography, Pritam’s attitude is that of optimism, resilience, and a willingness to find value and meaning even in difficult situations. She emphasizes the idea that individuals with disabilities can adapt and thrive, finding new opportunities for personal development and growth. Following the young man’s advice and the Assamese translation of Baby Halder’s book “Alo Andhari”- *Amanisar Pohar* (Light in Darkness) as models of inspiration, she sets out to write. However, initially her mind is clouded with confusing thoughts about where and how to begin and most importantly who would profit by it. She is not desirous of revealing the intimate details of her life in an autobiography and takes to publishing in regional newspapers which elicit mixed responses from her readers. One of her readers introduces her to the works of Elizabeth Barrett Browning, a writer whose creative output of works obscures the effects of her debilitating impairment. Throughout her autobiography, despite her apparent physical immobility, she exhibits volumes of imaginative and creative abilities. Soon after, Pritam devotes a section of her autobiography in describing the measures undertaken by the central government to construct a four-lane national highway cutting across their nearby areas. This results in a rapid increase in pollution and its resulting effects on the sick and the elderly. It becomes an ordeal for the narrator to cross the un-graveled roads and she has to be carried to the examination hall during her undergraduate exams. Soon after her exams, she resumes writing for the newspapers. She does not appreciate sympathy from her readers on account of her impairment and is much troubled by the assessment of her as “an encumbered woman writer” (Pritam 156). She does not want her physical disability to be the first reference point of her introduction. After dealing with anxiety and sadness, she takes her feelings of “suffering and loneliness to foster her creativity” (Pritam 160). Pritam’s statement reflects her desire for independence, equality, and

the opportunity to be recognized and appreciated for her talent and creativity, rather than being defined or limited by her physical disability. She chooses to use her personal experiences as a source of strength and inspiration for her writing, emphasizing her agency and determination. Old Age, infirmity and ill health strikes her parents and with such conditions she manages to write ten pages of her novel in the third-person. Stories of Franklin Roosevelt, Jessica Cox, Vick Fincal and Christopher Reeve serve as models of inspiration to her. She is also amazed by how the senses of touch and smell enables Hellen Keller to identify things and how she acquires speech. Her article dealing with her life ‘The Sun in a Cloudy Sky’ appears in *Amar Asom* on September 2, 2010. The narrator’s writings are published in *Amar Asom* serially under the caption Autobiography of Sarmistha. This is made possible by the then Chief Editor of the newspaper Homen Borgohain who encourages her to keep writing but tells her to avoid being sentimental (Pritam 174). As her writings about her life appear in the newspapers, she is able to connect to a wider audience and persons with different disabilities reach out to her for support. She also describes her encounters with other disabled persons from Assam who took to various creative pursuits to show that they are much more than just their disability. Pritam describes them thus: “Among them are Monica Das of Nalbari with rheumatoid arthritis who loses her ability of walking, Anindita Kalita of Guwahati- a victim of liver cirrhosis, Dhrubajyoti Das of Barpeta living with muscular atrophy, Prabodh Ranjan Sarma of Nagaon living with Becker Muscular Dystrophy, Paban Bora inflicted with rickets, Jatin Bora- a victim of nervous debility, Rashmi Rekha Bhuyan of Sonitpur and Prapti of Dibrugarh living with cerebral palsy, Jasmine Ara Begum of Mongoldoi with motor neuron disease, Ritumoni Das of Tezpur with his lower body completely dysfunctional and the Nepalese girl Jhumak Ghimere, who conquers the shame, loneliness and dishonor associated with her lameness and deafness” (Pritam 178-179). The purpose behind Sarmistha Pritam discussing these disabled individuals and their life stories in her autobiography is likely to highlight and shed light on the diverse

experiences of people with disabilities. By sharing the stories of these individuals, she aims to raise awareness about the challenges, discrimination, and societal attitudes that people with disabilities often face. It humanizes these individuals and shows that their disabilities do not define their entire lives. By including these stories in her autobiography, Pritam is advocating for greater inclusion and accessibility for people with disabilities in society, including in education, employment, and public spaces. She is inspired by the lives of these people who have devoted their lives “to the pursuit of the arts, to animate the beauty of life by creative vigour” (Pritam 177). In his essay, “Autobiography as Performative Utterance,” Michael Bérubé writes, “the conditions under which certain authors claim the authority of autobiography are sometimes exceptionally hostile to the claim” (11). Drawing a link between “marginalized narratives and the life-writing of people with cognitive disabilities, Bérubé argues that self-representation serves the radical and political function of declaring a self, worthy to be named—asserting, in effect, that it does matter who speaks and that the speaker is a legitimate self—which in turn disrupts the kinds of dehumanizing ideologies that equate difference with unworthiness, inferiority, and lack” (Berube 15). Pritam uses her “writing ability” to write herself into an able-bodied culture where disability is stigmatized as a sign of failure or inadequacy. During the course of writing her autobiography, her parents’ ill-health act as a major hindrance which she eventually overcomes and serially publishes her autobiography in 2010. As she firmly believes:

Painful days assail us, we bear them, and bear them we will always... every experience we face enriches us. Every setback opens up a path of life. So I have embraced all my experiences of happiness and sorrow, have been marching ahead with my dreams one after another... With the pen, which alone alleviated all my pain and suffering, firmly in my grip, I see a long, long road ahead. Along that I want to walk, want to forward my footsteps, all in mind.

(Pritam 184)



To sum up, Pritam's autobiography sheds light on the importance of inclusion and empowerment for people with disabilities. By sharing the stories of various individuals with disabilities, she emphasizes their abilities, dreams, and accomplishments, challenging the stereotypes and biases that often marginalize them. This aligns with the principles of human rights advocacy, which call for equal opportunities and the removal of barriers for all individuals, regardless of their abilities. Pritam's autobiography confronts the stigma associated with disabilities and strives to humanize individuals with disabilities. It portrays them as fully capable of leading meaningful lives and contributing to society, which is in line with human rights advocacy's goal of eliminating discrimination and prejudice based on disability. Pritam's narrative illustrates the power of self-representation. People with disabilities who share their own stories and experiences is a fundamental aspect of human rights advocacy. It asserts that individuals with disabilities have a voice, agency, and the right to be heard, thereby challenging ableism and promoting self-determination. Pritam also underscores the importance of education and the pursuit of dreams by individuals with disabilities. This aligns with human rights principles, which emphasize the right to education, employment, and the pursuit of personal goals without discrimination. Sarmistha Pritam's autobiography aligns with the principles of human rights, which aim to eliminate discrimination and promote the dignity and agency of all individuals, regardless of their physical or cognitive abilities.

**Envisioning a world beyond sight: Preeti Monga's journey of empowerment and advocacy in *The Other Senses***

Preeti Monga is a disability activist, entrepreneur and social worker who is working towards the development of the visually challenged. She is the founder and the CEO of the Silver Linings Trust and Silver Linings Services which are directed towards empowerment and the

inclusion of the visually disabled since 1987. In her autobiography- *The Other Senses*, Preeti Monga describes the embodied experience of blindness through various metaphorical references, providing a vivid description of themes and tropes and writing herself into an ableist society. Preeti Monga's *The Other Senses* (2012) and *Flight Without Sight* (2018) are personal accounts of living with optic atrophy. Monga's autobiography encourages us to attentively listen to the narratives told by and about blind individuals. It prompts us to delve beneath the surface and move beyond the clichéd portrayals of blindness often found in fiction and life-writing. It calls upon us to reassess, reinterpret, and reexamine our preconceptions about blindness. Furthermore, it serves as a reminder that our vision is not always a dependable source of information; appearances can be deceiving, and at times, other senses- represented here by the narrator- offer more trustworthy insights. Monga describes a self-reliant human subject by promoting inclusivity, equal rights, and social acceptance. Advocacy narratives often encourage the use of respectful and person-first language. For example, instead of saying "the blind," they promote saying "people with blindness" to emphasize that blindness is just one aspect of a person's identity. Recognizing that blind individuals, like all people, have diverse identities and experiences, the advocacy narrative considers how factors like race, gender, sexuality, and socio-economic status intersect with blindness to create unique challenges and forms of discrimination. Throughout Monga's autobiography, the narrator is envisioned in the society as the embodiment of deficit, lack and incapacity. Monga's autobiographical narrative has certain parallels with Shivani Gupta and Sarmistha Pritam in the sense that all of these individuals face additional challenges due to the inaccessible architecture of the city. In Monga's autobiography, she delves into domestic settings, memories from her childhood through adulthood, and everyday experiences that, although seemingly insignificant, raise important questions about how a blind person establishes their place in a predominantly sighted world on a daily basis. Mark Paterson in his essay "Blindness, Empathy and 'Feeling Seeing':

Literary and Insider Accounts of Blind Experience” (2014) asks “is the mechanism one of sympathy, the sharing of feelings of another (feeling-with), or the more specific projective identification of putting oneself in the place of another, empathy (feeling-for)?” (95). In documenting her life experiences in the form of an autobiography, Monga adds to the construction of social and cultural understandings of blindness in the present-day context. Central to my analysis is the consideration how Monga positions her narrative as a site of alterity and construction of a radical human subject which can serve as a significant signpost for human rights advocacy. The narrative also describes the problems faced by a visually impaired individual as she treads the disability hostile architecture of Indian cities. In her essay on disability, Alice Hall suggests that “blindness foregrounds and reconfigures the physical and phenomenological aspect of reading processes through the engagement with the technologies such as Braille, computer scanners, and through the attention to representation to sound, texture and smell in textual forms” (91). In *Sight Unseen (1999)*, Georgiana Kleege declares “I find it easy to imagine what it’s like to be sighted. I had to write this book to learn what it means to be blind” (3). This seems to problematize the idea of blindness as a stable category. Similarly, Hall quotes the observation of Beth Omansky who describes “the experience of being legally blind as living in the “borderlands of blindness”, occupying an interstitial position between sightedness and blindness implying that she can never identify with either category” (Omansky quoted in Hall 4). Similarly, Jorge Luis Borges describes his gradual process of going blind, but he also talks about the equation between blindness and complete darkness:

One of the colours that the blind – or at least this blind man – do not see is black... I, was accustomed to sleeping in total darkness, was bothered for a long time at having to sleep in a world of mist, in the greenish or bluish mist, vaguely luminous, which is the world of the blind. I wanted to lie down in darkness. The world of the blind is not the night that people imagine. (Borges 474)

What Borges seems to be suggesting here is that after losing the world of appearances, the task of the artist (the creative writer) is to create something new (477). Along a comparable vein, Monga while addressing her autobiographical narratives (*Flight Without Sight* and *The Other Senses*) to a sighted majority, does not allow her visual impairment to take precedence over her abilities. In her book, *Blindness and Writing: From Wordsworth to Gissing* (2017), Heather Tilley turns to the twentieth-century French feminist philosopher Hélène Cixous, who in questioning what it means for her, as a female author to write, explains: 'I write without seeing that I write, what I write' (Cixous quoted in Tilley 124). Cixous, who is among the feminist writers who have extensively delved into the possibilities of feminine writing outside of the patriarchal symbolic order, visits the scene of blindness in her text, 'Writing Blind'. Cixous observes that 'not seeing the world is the precondition for clairvoyance. But what does it mean, to see? Who sees? Who believes they know how to see?' (Cixous quoted in Tilley 125). Cixous privileges the category of blindness above the category of gender in her position as writer:

My nearsightedness is the secret of my clairvoyance ... I owe a large part of my writing to my nearsightedness. I am a woman. But before being a woman I am a myope [une myope]. Myopia is my secret.<sup>37</sup>

Writing from this secret space of blindness, Cixous privileges myopia above gender in her understanding of herself as writer. 'I am a woman' is a seemingly emphatic pronouncement of identity that is then undone by the caution that follows: 'but before being a woman I am a myope'. Cixous' myopia resonates with Monga's autobiography. Both of these women writers contemplated states of blindness to explore how touch and sound, in addition to vision, can shape our perception and understanding of the world and its narrative representation. Being

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<sup>37</sup> See Hélène Cixous, 'Writing Blind', in *Stigmata* (London: Routledge, 1998; reprint 2005), pp. 184–203 (p. 198). Cixous's discussion of myopia in the context of stigmata is relevant because early disability studies originated from the study of stigma, which revealed how all human differences can be stigmatized to align with dominant group's judgments. This connection between stigma and disability studies, along with Erving Goffman's work in "Stigma: Notes on the Management," warrants exploration.

acutely aware of the assumptions of visuality embedded in her culture, Monga tries to problematize the ideas of ocular-centrism prevalent in the society and humanizes blind individuals by emphasizing their capabilities, skills, and accomplishments. This challenges the assumption that blindness implies dependence or incapacity, undermining the societal bias that equates blindness with helplessness. Monga describes the unique strategies used by blind individuals to navigate the world. Autobiographical narratives on blindness showcase these adaptations, challenging the sighted bias that assumes everyone should conform to a single, sight-dependent mode of existence. Both of Preeti Monga's autobiographies, *The Other Senses* and *Flight without Sight* explore her journey from partial sightedness to complete blindness. She "utilizes memories from moments of temporary sightedness to construct an alternative narrative after losing her sense of sight. These settings and fragments of memories, spanning from childhood to adulthood, serve as platforms for experiencing alternative modes of consciousness" (Purkayastha 55). Monga begins her memoir by describing two encounters- at the movie hall and at the Ajmer Sharif shrine where she is mistaken for a person with a mobility impairment because of the invisible nature of her disability. The very act of writing about her experiences, she chooses to "surrender to the flight of fingers on the keyboard as they paint with the colours of words..." is an instance of turning all ocular centric prejudices on its head (Monga 5). The narrator is unable to decide on an adequate starting point of narrating the events that have transpired in her life as she writes:

As I sit at my computer this morning, writing about my life experiences, I am unable to resist the temptation of drawing for you the glorious pictures stored away in the closet of my reminiscence. I therefore surrender to the flight of my fingers on the keyboard as they paint with the colours of words, images of the glorious albums stored away, beginning with the oldest collection. (Monga 5)

Monga's autobiography describes "a connection between her partially failing eyesight, and the bodily memories associated with her other senses. During that time, she communicates and

navigates the world around her through her other senses. The narrative thus hints at an alternative site of perception and experience- “a new mode of making sense of the world around her” (Monga quoted in Purkayastha 56). She recalls that the roof and the floor of the house were not just physical objects but also materials that produced sound. Because of her visual impairment, her other senses, such as hearing, smell, and touch, play a significant role in her life. These include the sounds of footsteps and the gentle patter of raindrops, among others. (Monga 7-8). Georgina Kleege writes about the heightened awareness of the blind person to senses of taste, smell and touch (324). From her childhood, Monga remembers the evergreen forests in the vicinity and sound of the waterfalls at her grandparents’ place in Shimla. Likewise, due to her father’s transfer to Agartala in Tripura, her entire family has to move there and what remains in her memory is the house in Agartala surrounded by an “overgrown and shabby garden with a broken bamboo fence” with “unfamiliar sounds of creatures of the night, filling the air with a sense of thrill and mystery” (Monga 16). Cataloguing the series of her dreaded visits to the eye specialist- or “medical tyrants” as she calls them, she is subjected to various medical procedures which “become a never-ending trauma” (Monga 24). She writes:

At these clinics, I would have to undergo all kinds of strange tests and probes into my eyes and head. Without mercy, countless drops of atropine were forced into my eyes, ignoring the loud protests I emitted. No matter how much I cried or pleaded, nothing seemed to release me from painful injections and petrifying examinations. It took all my self-control to refrain from the powerful urge to strike the doctors while they breathed into my face, shining dazzling lights into my eyes. (Monga 24)

Through the use of phrases like “ignoring the loud protests,” “painful injections,” and “petrifying examinations”, Monga conveys the physical and emotional distress she experiences during these medical procedures which suggests a potential violation of the right to be free from cruel, inhuman, or degrading treatment, a fundamental human rights principle. Undergoing these tests, she feels powerless and subjected to procedures that induce discomfort

and fear. The narrator uses phrases like “breathed into my face” and “shining dazzling lights into my eyes” suggests invasive and intrusive examinations which violated her right to privacy and bodily integrity. Despite her initial discouragement upon learning about the permanence of her disability, she also finds a sense of relief knowing that this will bring an end to the unending hospital visits. In her narrative, Monga writes that she is mentally preparing herself for embarking on a journey that is beset with numerous impediments.

Before continuing to paint my life’s canvas, I would like to mention some more of the incredible efforts nature made to prepare me for the disability I was to live with. Many idle evenings at my aunt’s home were spent listening to stories read to me, and the one of Helen Keller truly fascinated me. I was deeply moved by the harshness of her multiple disabilities and greatly admired the heights to which she rose. I have very often drawn inspiration from the fact that if she could achieve so much with three out of her five senses impaired, what stopped me from doing the same with four of mine perfectly intact? (Monga 26)

Much to her astonishment and dread, Monga is transformed into an object of pity within her circle of friends and family. Despite her failing eyesight, her mother never discourages her to pursue her interest in embroidery. Her father’s job profile affords her the opportunity to travel across road to various north eastern states and she has the privilege of “capturing the phenomenal beauty of the world with the dysfunctional camera of her sight” (Monga 35). A significant portion of Monga’s recreation of the memories of her growing up is facilitated by her photographic memory. Alice Hall quotes Jacques Derrida, who, for example, “in *Memoirs of the Blind* (1993), takes portraits of blind people in the Louvre art gallery as his starting point. He describes that there is discomfort and fascination involved in the act of looking at the blind. Derrida uses the figure of the blind draftsman to explore the way in which whenever someone writes, draws or paints, they necessarily look away from their subject and instead re-create the image from the one that is in their mind’s eye. In this sense, memory always “supplements” sight” (Derrida quoted in Hall 13):

A hand of the blind ventures forth, alone and disconnected... it feels its way, it gropes, it caresses as much as it inscribes, trusting in the memory of signs and supplementing sight... This eye guides the tracing outline; it is a miner's lamp at the point of writing, a curious and vigilant substitute, the prosthesis of a seer who is himself invisible. (Derrida quoted in Hall 13)

For Derrida, therefore, “creative and aesthetic moments are bound up by those moments of not seeing” (Derrida quoted in Hall 13). The hand that gropes at the dark represents a movement towards knowledge. In her autobiography, Monga vividly portrays the obstacles she encounters when navigating institutions that lack proper facilities to accommodate the needs of a blind person. Despite the myriad challenges she faces, Monga eloquently depicts the growing passion she develops for classical music. Due to the advances in medical technology, she is offered a kind of spectacle through which she can “read some printed material in controlled environment” (Monga 54). Like Sarmistha Pritam, Monga describes the various alternative modes of self-expression through embroidery, writing and reading. Not long before, she also learns to use her father's typewriter- a skill which helps her bridge the gap between the world of the blind and the sighted. She never allows her disability to come in the way of her progress:

I never allowed the handicap of not being able to read and type simultaneously become a constraint in mastering typing skills. Rather, I accepted it as a challenge, and formulated an innovative strategy to surmount this central problem by typing self-constructed sentences for the purpose of practice. I wrote about the day, the weather, the city, the family, and anything else. I could imagine effortlessly and swiftly; and of course, there would be letters that would not give me the pleasure of communicating my side of the stories and news, but elicit exciting responses as well. (Monga 60-61)

She becomes so immersed in the act of writing that the sound of the keys striking against the paper as she types, is music to her ears. This particular act of writing is a momentary solace from the prejudices and biases that she is subjected to. As she writes:

The sound of the keys clicking on the paper fitted on the roller was like music to my ears, and the ever-increasing speed of the flight of my fingers on the keyboard was



quite wonderful. This gave me an enormous sense of freedom and accomplishment once I had mastered the contraption. Now, I could write just like everyone else, in complete contrast to the terrible sense of defeat and helplessness I was consumed with in relation to so many other things. (Monga 61)

The description of the sound of keys clicking on paper and the increasing speed of the fingers on the keyboard conveys a positive and almost musical experience. This suggests that, for Monga, the act of writing is not just a functional task but something sensory and enjoyable. Monga connects the act of writing with a feeling of freedom. This is symbolic of overcoming the limitations and stereotypes associated with visual disability, demonstrating that she can engage in activities, such as writing, just like everyone else. Monga contrasts her newfound ability to write with the “terrible sense of defeat and helplessness” she feels in relation to many other things. This highlights the transformative power of writing in her life, serving as a realm where she can assert control and independence despite other challenges. By expressing the ability to write “just like everyone else” and emphasizing the contrast with other areas of struggle, Monga positions herself as a self-reliant human subject. Writing becomes a means through which she asserts her agency, defying societal expectations and overcoming the limitations imposed by her visual disability. Monga describes her attitude of resilience, determination, and exercises her creativity in the face of her disability. She approaches challenges as opportunities for growth and does not let her physical limitations define her or hinder her pursuit of goals. The act of writing allows Monga to participate on an equal footing with others, challenging any perceptions or societal norms that might marginalize or exclude her. In her autobiography, the narrator describes several instances showcasing the prejudiced attitude of the people towards her, owing to her disability- the denial of her school, the music teacher, her prospective bridegrooms and even the hotel staff where she is recruited as a trainee. At the Blind Relief Association in Delhi, she experiences differential treatment when she passes off as a sighted person. Her hopes for a secured and “normal” life after marriage to Keith comes

crushing down when she is subjected to physical and verbal abuses to an extent that she contemplates suicide. She soon realizes that achieving financial independence is the most viable way to combat her feelings of shame and depression. Consequently, she joins aerobics classes and is assigned the role of teaching aerobics to children at the National Association of the Blind. Despite facing discrimination, she persists in her journey. Like Valliappan, Monga experiences institutional discrimination. After ending her violent marriage with Keith, Monga finds in Sunil, a mental pillar who helps her shield her excruciating pain (Monga 134). Her public image undergoes much transformation after she starts working as an aerobics instructor, she is invited as a resource person for “sports and fitness” by the Disabled Peoples’ International in Calcutta. Monga also demonstrates the indifferent attitudes of her co-workers at her workplace and how they despised the entrepreneurial abilities of a visually impaired woman. Despite these initial deterrents, her flair in promotion, sales and supply is recognized and is all over print and electronic media and she is awarded on several occasions for her social work. Due to her growing public presence, she is invited by the Ability Foundation to a disability-focused fashion show. She receives an invitation from Nestle for a motivational seminar, she is inspired and this is one of the significant moments in her life where she exercises agency and reclaims control over her self-representation. This particular event also provides the necessary prelude for conducting similar awareness training campaigns for her NGO- Silver Linings and delivering TED talks. She concludes her autobiography by narrating her transition from a sheltered territory into the realm of the unfamiliar, laden with the challenges that confronted her. She finishes by stating, “I have been fortunate to have successfully ventured into the unknown, chasing my dreams even in the absence of sight, holding onto the rope of faith and relying on the wings of ‘the other senses’” (Monga 177). Throughout her autobiography, Preeti Monga raises questions about the relationship between knowledge and sight by providing a personal perspective on the challenges and discrimination faced by

visually impaired individuals, shedding light on issues related to equal access, accommodation, and societal attitudes. Her autobiography may serve as a platform for advocacy, raising awareness about the rights and needs of visually impaired individuals, and challenging the violations of those rights. By describing the intersection of visual impairment with other aspects of identity, such as gender, race, or socio-economic status, her autobiography can inspire and empower both visually impaired individuals and society at large to support human rights and inclusivity. Monga also notes that blindness is not necessarily antithetical to creative and imaginative possibilities. This can indeed suggest ways of rethinking our conceptions about embodied narratives and the process of representation itself. This chapter tried to examine the life-writing of Monga, Valliappan, Pritam and Gupta to foreground the different ways in which the human subject chooses to point out various human right violations, debasement of their human status by writing [righting] their life stories. The narrators of the aforementioned texts narrativize their experience in relation to human rights in their lived environment and question the idea of what constitutes the human subject by objecting to the various human right violations in the course of their narratives. What I have essentially tried to show in this chapter is that, life-writing, when examined through the lens of human rights and in the context of disability and mental illness, offer a profound understanding of the challenges, resilience, and advocacy of individuals facing these conditions. The diverse ways in which characters exhibit agency demonstrate various paths to restoring and reclaiming their subjectivity. Although the life narratives highlight institutional and ideological forms of disablement that compound the challenges of navigating urban environments, nonetheless, the life-writing texts transition from portraying individuals as abject to empowering subjects who, through their narratives, actively engage with and reshape societal perceptions, redefining their identities and rights.

## Conclusion

### POEMS WITH DISABILITIES

Jim Ferris<sup>38</sup>

I'm sorry – this space is reserved for poems with disabilities. I know it's one of the best spaces in the book, but the Poems with Disabilities Act requires us to make all reasonable accommodations for poems that aren't normal. There is a nice space just a few pages over – in fact (don't tell anyone) I think it's better than this one, I myself prefer it. Actually, I don't see any of those poems right now myself, but you never know when one might show up, so we have to keep this space open. You can't always tell just from looking at them, either. Sometimes they'll look just like a regular poem when they roll in... you're reading along and suddenly everything changes, the world tilts a little, angle of vision jumps, your entrails aren't where you left them. You remember your aunt died of cancer at just your age and maybe yesterday's twinge means something after all. Your sloppy, fragile heart beats a little faster and then you know. You just know: the poem is right where it belongs.

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<sup>38</sup> Jim Ferris is a performance artist, poet and professor for the Disabilities Studies Program at the University of Toledo in Toledo, Ohio. He has authored several books and journals on poetry and disability. [https://www.amnesty.org.uk/files/201901/Poems%20with%20Disabilities%20by%20Jim%20Ferris.pdf?VersionId=Xw6YNNREZoeEEI\\_SV5YA\\_NuI4BM7VkJ](https://www.amnesty.org.uk/files/201901/Poems%20with%20Disabilities%20by%20Jim%20Ferris.pdf?VersionId=Xw6YNNREZoeEEI_SV5YA_NuI4BM7VkJ)

I encountered this poem when I was more than a year into my PhD research on the intersection of disability, mental illness, and literature. Therefore, it did not directly inspire my research, but it nevertheless encapsulates the core ideas of my research. Jim Ferris's poem, "POEMS WITH DISABILITIES," is a powerful poem that addresses the issue of selfhood and narrative agency in the context of disability. It challenges societal norms and expectations surrounding disability and highlights the need for accommodations and inclusion in the literary world. The poem begins with the assertion that the space is reserved for poems with disabilities. This immediately sets the stage for discussing the importance of representation and inclusion for marginalized voices in literature, especially within the context of disability. It raises the idea that poems with disabilities have a right to exist and be heard, challenging traditional notions of what constitutes a "normal" poem. The mention of the "Poems with Disabilities Act" alludes to the legal framework for promoting inclusion and accessibility in society. This draws a parallel to real-world disability rights legislation, underlining the importance of accommodating and respecting the needs and perspectives of disabled individuals. The poem explores how a poem with disabilities may appear "normal" at first glance but can suddenly shift the reader's perspective and challenge their assumptions. This mirrors the experiences of disabled individuals who may not conform to societal stereotypes or expectations but have unique and valuable perspectives to share. The poem elicits a sense of empathy in the reader. It describes the moment when a reader's world shifts, prompting them to reflect on their own experiences and the experiences of others. This connection to personal narratives reinforces the idea that disability is a part of the human experience and should be acknowledged and valued. The poem subtly highlights the agency of the poem itself, suggesting that the poem knows where it belongs and should be valued on its own terms. This concept extends to the agency of disabled individuals in shaping their own narratives and having their voices heard. The poem

challenges the idea that disabled individuals should conform to others' expectations and instead encourages them to assert their narratives and perspectives. It calls for the inclusion and accommodation of diverse voices in the literary world, challenging traditional norms and highlighting the transformative power of personal narratives. The objective of this dissertation has been to examine life-writing and fiction on physical disability and mental illness written in the early twenty-first century in India. Through an array of select texts, I tried to show that these life-writing and fiction are therapeutic counter-narratives in the sense their narratives can serve as markers for individuals to take control of their mental health, make informed choices, and advocate for themselves. It may also empower writers to share their stories and make a difference. Therapeutic literary narratives may also serve as valuable resources for researchers, clinicians, and mental health professionals. They provide insights into the lived experiences of individuals with mental illness and physical disabilities by foregrounding the healing and therapeutic potentials of writing. The selected texts posit an alternative idea of selfhood which is ambiguous and hybrid in the unique ways in which the characters choose to exercise agency and voice. I examined the collaborative narratives of the caregiver and the care-receiver in the selected texts in how they contribute to a relational identity and how family, genre and gender may modulate this understanding. The narrators of the texts also foreground a complicated relationship with their bodies and memories in the embodied narratives. The dissertation also tried to look at how some of these texts serve as human rights advocacy narratives which may serve as signposts for promoting inclusiveness and social change. The first section of the introduction examines the ideas of selfhood and narrative agency in the context of life-writing and fiction and then provides a trajectory of the development of the fields of literary disability studies, mad studies, medical and the health humanities. The Introduction then identified the current research gap and outlined the aims and objectives of the dissertation. It also contextualized the fiction and life narratives within a particular socio-historical setting.

The first chapter of the dissertation titled “Therapeutic counter-narratives”, tried to examine how the selected life-writing can serve as therapeutic counter-narratives to a clinicians’ understanding of disability and mental illness which may not always take the intricacies of the lived experiences of the disabled person into account. I tried to argue that the select literary narratives may be read as psycho-therapeutic counter-narratives because the act of writing not only helps in assuaging distress but also attempts at expunging the traces of the trauma. This therapeutic story-telling is conducive in creating narrative agency, a sense of connectedness and describing alternative modes of self-expression. The selected narratives try to augment and supplement the existing biomedical narratives on mental illness and physical disability. My study does not aim to establish that writing is the ultimate source of recovery or is therapeutic. It is not a survey intended to investigate how writing or reading can heal a person’s health issues. While some of the writers discussed in the preceding chapters have mentioned therapeutic intentions or personal benefits from their writing, such as Gayathri Prabhu, Shivani Gupta, Shreevatsa Nevatia, Sarmistha Pritam, and Pankaj Varma, the autobiographical or fictional instances of therapeutic narratives is not the core idea explored in this dissertation. Instead, I try to signal that literary text may incorporate therapeutic elements. My dissertation focuses on the texts themselves, examining how they problematize disempowering assumptions about physical disability and mental illness, introduce innovative language for experiences and provide a transformative perspective on disability and mental illness. This approach allows us to consider the ways in which these texts may incorporate therapeutic elements. I try to examine how these narratives reshape our understanding of disability and its implications, rather than proving or disproving therapeutic effects.

The second chapter of the dissertation titled “Caregiving and narrative agency” focused on certain life narratives and fiction which I intend to classify as caregiving narratives. I tried to argue in the second chapter, the centrality of the caregiver’s role for the individuals’ coming

to terms with their selfhood and subjectivity. The caregiver- care-receiver relationship is an evolving relationship, and this relationship is negotiated through a mode of participatory narration which promotes empowerment by pointing out the discriminatory practices that are apparent in the realm of physical disability and mental illness. The chapter also tried to explore in depth the various nuances of the caregiving relationship and certain caregiving dilemmas. As Thomas Couser observes, 'genre is not about mere literary form; it is about force- what a narrative's purpose is, what impact it seeks to have in the world' (Couser 9). I also tried to explore the particular social force and some of the ethical questions that caregiver life-writing and fiction seem to raise. Through a close-reading of select texts, I tried to address the intersections of gender, caregiving, family, narrative and relational identity. The texts I examine in the chapter include Himanjali Sankar, Pankaj Varma, Shama Husain and Tito Mukhopadhyay- which are either authored by a person living with a physical disability and mental illness or by a family member- who is either the parent or the child of the narrator involved in caring. In describing the lived experience of the disease, I maintain that these narratives can be productively situated within the context of the boom of life-writing in the past few decades that Alice Hall identifies. (Hall quoted in Smith and Watson 20). Following Rebecca Bitenc's lead, in my argument, I contend that caregiver's life-writing and fiction not only encompass the caregiver and the family member's shared life-stories, but often focuses on the family member's genealogy to an extent that life-writing or fiction may not. The caregiver assumes the role of a researcher, delving into the psychological, economic and social causes that shape the experience of living with disability and mental illness. This engagement provides the caregiver with a meaningful activity in the face of the health condition, which initially challenges the concept of self and defies meaning. As noted by Rebecca Bitenc, caregiving narratives enable the authors to maintain a connection with a declining family member by reconstructing, and sometimes revising or re-envisioning their previous



relationship. These narratives are, as Arthur W. Frank observes regarding illness narratives in general, meant for others. Frank sees them as fulfilling a moral duty to bear witness. Mary Gordon delves into “the conflicting demands of witnessing, where writing is a form of bearing witness, and not to expose others” (4). Gordon suggests that “she has made the most dishonourable choice: to speak and then confess her own (superior) knowledge of the dishonour of speaking” (4). The caregiver-narrator grapples with this dilemma, attempting to strike a balance between their need to tell their story and the imperative to not harm the person living with the disability, in the process. This conflict becomes evident when the narrative reveals certain details that the subject has requested not to be disclosed. Caregiver’s narratives represent dialogue with the person living with disability or mental illness, the person’s behaviour and attempts to convey their thoughts, feelings and emotions. In this chapter, I tried to explore the relationship between the caregiver and the care-receiver in the context of the family and to what extent this identity and relationship is maintained through relationships and through relational life-writing and fiction.

The objective of the third chapter titled “Embodiment, subjectivity and self-identity” was to focus on the role of embodied self which serves as a locus or focal point of remembering and narrating experiences of living with disability and mental illness. I tried to show how the story is inscribed on and written by the body and the centrality of memory in the embodied narration. I focus on the embodied aspects of disability and mental illness in the texts of Shabri Prasad Singh, Jerry Pinto, Amandeep Sandhu, Joginder Paul and Anirban Mukherjee. The embodied aspects present a nuanced portrait on the phenomenological lived experiences of mental illness and physical disability. Through a close reading of the aforementioned literary texts, I examine how notions of embodied selfhood (Kontos 2005) and embodied communication (Killick and Allan 2001) can be productively employed in reading the selected narratives. I try to examine how individuals with disabilities and mental illnesses undergo shifts

in their self-perception. These alterations in self-awareness are expressed through emotions and physical behaviours. The narrators of the select life-writing and fiction foreground their corporeal difference as a creative force, as a disruptive force, as an extension of the self, amongst others. The self-referentiality of the select texts also point to the provisional status of “abled-identity”. In the select texts, the individual’s self-identity is deeply connected to their physical and sensory experiences. In the context of disability and mental illness, this concept underscores the importance of recognizing that one’s identity is not solely defined by their condition but also by their lived experiences and how they perceive themselves within their bodies.

The fourth chapter of the dissertation titled “The self-reliant human subject- Narrativizing human rights” tried to examine select life narratives which I maintained can be productively situated within a human-rights framework. The selected texts of Shivani Gupta, Sarmistha Pritam, Preeti Monga and Reshma Valliappan are crucial in depicting various forms of human rights violations in the context of disability and mental illness. These texts attempt to create connection and care for the disabled people in the reader’s imagination- what Cristopher Krentz identifies as “kinship<sup>39</sup> as a step crucial to achieving meaningful disability human rights in the world, although he acknowledges that human rights alone is not sufficient for justice. The titular “elusive” points to a relationship that is not direct but is happening and warrants consideration. Joseph R. Slaughter argues that fiction, particularly bildungsroman or coming-of-age novels, and human rights share a common focus on the individual’s role in society. These two ideological constructs complement each other by addressing individuals’ relationships within their societies.<sup>40</sup> Scholars in this field use human rights as an analytical

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<sup>39</sup> See Cristopher Krentz’s “Introduction” in: *Elusive Kinship: Disability and Human Rights in Postcolonial Literature*. Temple University Press, 2022.

<sup>40</sup> See Joseph R. Slaughter’s *Human Rights, Inc.: The World Novel, Narrative Form, and International Law*. Fordham University Press, 2007.

framework for studying literature, as it can effectively illuminate and bear witness to issues related to rights. As Pramod Nayar states, “literature provides a unique pathway to explore the concept of humanity and the experiences of those marginalized from it” (v). This illumination, he suggests, is something that legal and political discourse alone cannot adequately offer. The selected life-writing depict instances of human rights violation and debasement of the subjectivity of the disabled person. However, the narratives are crucial in foregrounding the rights of the disabled in various ways through their life-narratives. James Dawes emphasizes the importance of storytelling to address human rights violations. This raises challenging questions about how to narrate the unimaginable, who holds the authority to tell these stories, and the risk of retraumatizing survivors when sharing their experiences.<sup>41</sup> Additionally, Elizabeth Swanson Goldberg and Alexandra Schultheis Moore note that the field of human rights scholarship is marked by both controversy and a strong commitment to social justice (12). Traditionally, critics have focused on literature that portrays extreme violations like torture, genocide, and violence to explore the connection between storytelling and human rights. Nevertheless, Nick Mansfield highlights that even fictional depictions of everyday life can be significant in this context. He suggests that literature’s most valuable contribution to the discourse on human rights often arises from areas where rights are not explicitly mentioned or recognized, a perspective that aligns with this study as most of the works it analyses do not overtly reference human rights (112). In this chapter, the narrators of the selected life-writing problematize the idea of victimhood by navigating and grappling with their everyday experiences. In the course of Indian life-writing and fiction, the exploration of the selfhood and agency becomes particularly nuanced. The idea of selfhood and narrative agency takes centre stage as the aforementioned narratives not only depict instances of human rights violations but

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<sup>41</sup> See James Dawes’ *The Novel of Human Rights*. Harvard University Press, 2018.

also actively engage in reshaping the discourse surrounding the rights of the disabled and the mentally ill. Moreover, the intersection of literature and human rights, as acknowledged by Pramod Nayar, takes on a distinct character in the Indian literary landscape. The unique pathway provided by literature becomes a means to explore the concept of humanity and the experiences of those marginalized from it, fostering a deeper understanding of the challenges faced by individuals with disabilities.

The extensive body of life-writing and fiction in regional languages that explore the various Indian perspectives on disability and mental illness is beyond the scope of this dissertation. The dissertation restricts itself to specifically examining the autobiography and the memoir genre out of the vast corpus of life-writing. Given the ethical considerations inherent in researching topics like physical disability and mental illness, especially as a provisionally able-bodied researcher, I approached the subject matter with sensitivity, respect, and empathy. However, for prospective researchers interested in the field of literary disability how do you assess the confusion created through the identity of the inspector in the play life-writing and fiction within the context of other cultures. Moreover, there is a potential research avenue in exploring the intersection of disability and mental illness narratives with photography and paintings. Investigating how these forms of artistic expression contribute to or challenge prevailing perceptions and representations of disability and mental health could offer valuable insights into the broader cultural discourse. Along similar lines, it may be productive to examine the role of digital platforms and social media in shaping narratives related to selfhood and different health conditions in the Indian context particularly, and the South Asian context, generally. The study also acknowledges the need for research in various genres of life-writing such as diaries, testimonies, blog-posts, journals, letters, biographies, travel writing and oral histories of disability and mental illness. Despite recognizing the distinct challenges faced by the physically disabled and the mentally ill, the research adopts an

intersectional perspective to understand the complexities within these experiences. The article of Ryan Thorneycroft on “Crip Theory and Mad Studies: Intersections and Points of Departure” and Elizabeth Donaldson’s book on *Literature of Madness: Disability Studies and Mental Health* has been crucial to my research. Emphasizing the revisable, contingent, and permeable nature of crip and mad identities, the study employs a post-structuralist, narratological, and intersectional reading of these health conditions. An interested researcher can also explore how the idea of story-telling and narrative-based approaches can be used in healthcare to improve patient well-being, enhance the doctor-patient relationship and aid in the healing process. Potential research avenues include examining narrative-based approaches in healthcare to improve patient well-being, enhance doctor-patient relationships, and aid in the healing process. Exploring digital health narratives and the construction of doctor-patient relationships in such contexts, using autoethnography to study personal experiences of illness and embodiment, and delving into palliative care and literary gerontological narratives are all promising areas for further exploration. These areas, I propose, present opportunities for research, scholarship and practical applications to improve healthcare, enhance human rights, and better understand the role of literary narratives in the lives of individuals and communities.

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