

Contextualizing Illness: Analyzing the Relevance of Illness Narratives in Understanding Mental and Physical Disability

Daisy Priya Gogoi¹, Kakoli Bonya Gogoi²

^{1,2}Assistant Professor, Khowang College

Abstract:

A severe illness, whether physical or psychological, has the power to redefine a person's existence and reality. It effects the individual's ordinary life, his emotions, moods and behaviour and reduces him or her to a shell of what they used to be. While it is true that medical sciences have been effective in eliminating various diseases, there exists a gap between the healer and the healed. The physician only looks at the patient as a subject for diagnosis or a project, a number or a diagnosis. What they fail to understand is how grave of an emotional scar is caused by the disease. In the select narratives an attempt has been made to understand how illness narratives are crucial to understand the individualistic experience of illness and also to bridge the gap between the healer and the victim. Moreover, it also reveals how illness takes over the lives of the victims and makes them feel unsafe in their own bodies- as if being exiled from their own home.

INTRODUCTION

"Confession is not an act of courage. It is more cathartic than it is brave."

- Shreevatsa Nevatia, *How to Travel Light*

Disability, be it mental or physical, like a parasite, sucks out the balance from an individual's life and takes away their control of their own behaviours and actions. This helplessness and emotional toil of the persons suffering from disease can be appropriately understood with the help of illness narratives. Illness narratives are stories or personal accounts of individuals who have lived through phases of illness, physical or mental, and experienced its consequences. Such narratives are often in the form of memoirs, biographies or autobiographies. In the case of chronic diseases, illness significantly affects people's everyday lives, the experiences and perspectives being articulated in illness narratives. These narratives are directly related to the discipline of narrative medicine which marks the intersection of the humanities and clinical or therapeutic practices. Narrative-based medicine has emerged as an approach to illness in which health care providers are equipped with a better understanding of the patients' complex and inimitable experiences so that they can provide effective health care.

In this paper, two illness narratives, namely, Shreevatsa Nevatia's *How to Travel Light: My Memoir of Madness and Melancholia* (2017) and Shormistha Mukherjee's *Cancer You Picked the Wrong Girl: A True Story* (2021) have been taken up for study. A journalist by profession, Kolkata based writer Shreevatsa Nevatia was first diagnosed with bipolar disorder, a mental health condition that causes extreme mood swings that include emotional highs, also referred to as mania or hypomania and emotional lows or depression. Nevatia's memoir *How to Travel Light: My Memoir of Madness and Melancholia*

delineates how society misunderstands an individual's mental health experience and very readily attaches stigma to people when they are vulnerable and honest about their mental instability. On the other hand, Shormistha Mukherjee's memoir *Cancer You Picked the Wrong Girl: A True Story* is a meticulous account of the arduous journey of diagnosis and treatment of a breast cancer patient. The narrative resonates with thousands of other women who have undergone similar experiences; however, what makes the narrative extraordinary is the candour with which the writer tells her story, with an exceptional tint of humour and wackiness. Both these narratives provide insight into the unknown territory of the psyche of a diseased person, full of myriad experiences and musings, exclusively undergone by the patient, experiences which cannot be understood by an outsider. Herein comes in the role of such illness narratives into the realm of medical science where the knowledge of such narratives bridges the gap between the patient and the healer and thereby enhances the clinical effectiveness.

OBJECTIVES

The objective of this study is to understand how illness narratives are crucial to recognize the individualistic experience of illness and also to bridge the gap between the healer and the victim. Moreover, attempt is also made to comprehend how illness takes over the lives of the victims and makes them feel unsafe in their own bodies- as if being exiled from their own home. Furthermore, the study also reveals how personal narratives give the victims of illness a sense of authority, something which they perhaps never had while they fell victim to their illness. The healing and cathartic power of illness narratives is also analyzed through the paper.

METHODOLOGY

For this paper, the analytical method is applied. The primary sources for the paper are the two texts- Shreevatsa Nevatia's *How to Travel Light: My Memoir of Madness and Melancholia* and Shormistha Mukherjee's *Cancer You Picked the Wrong Girl: A True Story*. Secondary resources such as documentaries, podcasts and body theory have been used. Michel Foucault's body theory is extensively used which is crucial in understanding how the victim feels unsafe and foreign in his own body due to the disease or illness.

DISCUSSION

A severe illness, whether physical or psychological, has the power to redefine a person's existence and reality. It affects the individual's ordinary life, his emotions, moods and behaviour and reduces him or her to a shell of what one used to be. While it is true that medical sciences have been effective in eliminating various diseases, there exists a gap between the healer and the healed. The physician only looks at the patient as a subject for diagnosis or a project. The diagnosis that he would make or any other medical record related to it would not reflect the personal experience of illness. What they fail to understand is how grave an emotional scar is caused by the disease on the victim. He or she is completely stripped of any form of control of their own emotions, behaviours and actions. However, for medical specialists, the patient's symptoms are important for arriving at a diagnosis. More often than not, they ignore the emotional traumas or the relationships and conditions of their daily life that directly or indirectly impact their illness, thereby making the experience of illness non-subjective. This generalization of the illness is the primary factor responsible for the wide gap between the physician and

the patient. Only providing medicines without offering an emotional support makes the patient lose faith over the treatment, as in case of Shormistha:

“I knew the medicines were wrong for me, and so was the doctor. So, in a desperate cry for help, I posted a message...telling these strangers who I had gotten to know online that I was feeling like I was going mad.” (Mukherjee 67)

In the first personal narrative, Shreevatsa Nevatia narrates his experiences as a victim of manic depression. At the beginning of the *How to Travel Light: My Memoir of Madness and Melancholia*, we find Nevatia being sent to a wellness centre and rehabilitation clinic because cannabis had been found at his home. He narrates how he had been diagnosed with bipolar disorder and to what extent he had been an addict of cannabis. For his treatment, he was assigned therapy. Medically, his illness would be termed as someone who was suffering from drug abuse. His therapist called him in and along with two others; he had been made to attend a therapy session that required the reading of a chapter that described the effects of drugs on the brain. Nevatia came out disappointed. As we read further into the work, we get a glimpse into his past, his present and his escapades. Whereas medics see him as a subject of drug abuse; the narrative reveals the emotional wreck he was. He used to lash out at his parents who visited him and was never able to establish a proper relationship with any girl. It is his narrative that reveals his emotional pain. He writes how he regretted arguing with his parents and how much he wanted to cry out in frustration but could not. He was a seeker of true love like in the novels he wrote, but could not establish a long-lasting relationship because of his own childhood trauma. Satyah, his cousin, had taken advantage of his childhood curiosity and made him engage in intimate activities that were queer as well as incestuous. He felt a thrill doing those immoral things but also feared that he was committing sins punishable by God since his grandmother taught him about religion. Thus, the bipolarity in him was present since his childhood. It was not simply the marijuana or the alcohol. To fully understand Nevatia's bipolarity and to arrive at the right method of recovery, not only in physical sense but emotional as well, illness narratives are the key.

“When reduced to a sum of their symptoms, bipolar patients are often indistinguishable. Stories of mania and depression only have to be slightly tweaked for them to be relatable.” (2127)

Every individual's experience of illness and their past is unique and subjective. Therefore, to generalize all victims of bipolar disorder or any other disease is a fatal mistake. Until and unless the emotional pain and trauma is addressed and treated, the victim cannot recover themselves. It is with the help of personal or illness narratives that this solution can perhaps be reached. Illness narratives or narrative based medicine will help breach the gap between the patient and the healer or the physician essential for the healing of the victim.

Medical diagnosis only takes into accounts of the symptoms and the cause-effect logistics. However, an illness is more than just a number or a diagnosis. The individual's relations, his emotional stressors, the work environment, the personal complications, etc. contribute and influence the psyche of the victim, thereby making the experience of illness personal and unique to each. The body becomes a foreign being for the victim as he/she is unable to take authority of it. The illness completely dominates his/her emotions and actions. This subjective experience can only be understood through the personal narratives written by the victims themselves in the form of autobiographies or memoirs. When we read Shormistha Mukherjee's *Cancer, You Picked the Wrong Girl*, the loss of authority could be felt on an explicit level. Being a bold and self-made woman, Shormistha's world comes crashing down when she learns that the tiny lump in her breast is actually a fatal illness- breast cancer.

“My mind was moving in slow motion. Everything was very clear, but happening very slowly. She understood. She’s probably seen patients go into that kind of shock. Where you just can’t comprehend what is being said.” (Mukherjee 25)

The reality of it makes her lose her confident and vivacious nature. Never had she felt so foreign and unsure of her own life as in that moment. Although she had her husband, her mother and her friends who supported her, she felt as if no one could understand her. Shormistha underwent chemotherapy for which she had to shave her head. Unlike her normal diet, she had changes in her diet which was a constant reminder that she was no longer normal. Losing the way she once lived and enjoyed life outdoors or at parties was life changing. Everything changes too fast and too drastically for her, and with every little change, she felt herself slip all the more every day.

Shormistha’s life “was in pieces” (28) she writes. She realizes that now, she is just another one of those victims of an illness for the doctors – “Every time I walk into a hospital, that file will be my identity” (29) she states. Furthermore, she had to sacrifice her nipple as the lump was close to it. To lose a part of one’s body, something that defines her as a woman, was traumatic. Mukherjee narrates how she did not cry or go into hysterics. Rather she underwent an out of body experience. This can be related to the body theory of Foucault, who sees the body as a site of power, as well as of discipline and control. It is the body which is important as it eventually dictates the internal state of the individual.

“Foucault prioritizes the body as the site of operation and exercise of power, and argues that power operates on the body to produce the soul, the psyche, subjectivity, personality and consciousness; and in turn, it is through this soul that power is exercised on the body (McLaren, 2002). This notion of subjectivity, as commented by Deleuze (2006), is a “folding” or doubling: the inside is an operation of the outside; the exterior produces the interior (the soul) by a doubling, a folding, a reflecting back on itself. In this sense, the human subject is constituted by the various operations of power in history and culture that impinge on him. To be more specific, power exerted on us makes us what we are - bodies subjected to power; before being constituted to be a subject who can speak, think, judge and act, “man” is only a marionette-like, subservient, silent and manipulable body.” (Li 55)

Thus, as stated, if it is the “exterior” that produces the “interior”, the body is important as it affects and manipulates one’s emotional and mental state. With the experience of losing the control of the body, the emotional and mental sanity of an individual is driven into panic, making them break down no matter how strong emotionally they once were. Perhaps this is why torture is used as a means to break strong warriors and their resolve. Illness then, is like a cruel torturer relentlessly punishing the victim and making them suffer.

This control is lost by the victims of illness, just as we see in the case of Mukherjee. She can no longer decide how to live or if she does not want to sacrifice that vital part of her body. Furthermore, as a female, the breast is an organ that defines her as a woman and a mother. She does not want to sacrifice her nipple and feel handicapped. However, the other option was dying. If she wanted to survive, she had to live by the rules dictated by the disease. Furthermore, her emotions are in turn effected, reducing her to a mere tool at the hands of the illness. Similar is Nevatia’s case. There are incidents which he narrates where he lashes out at his parents and even his friends who care for him and only want what is best for him. However, because of his bipolarity, he ends up behaving in ways that he regrets later and is even embarrassed remembering those events. His body is affected by the cannabis he takes and the sinful acts he commits with his cousin. This in turn fills him with regret and later, it forces emotional reactions out

of him that not only further ruins his mental and emotional sanity, but brutally destroys the relationships he has with his loved ones.

Thus, episodes of illness that victims undergo put them in a place where they feel as if their identity is lost and their emotions and actions are no longer their own. If considered in terms of Diaspora which refers to the displacement from one's homeland, the metaphor of "The body is a house" can be applied. When the illness takes control, it is as if the victims are exiled from their own bodies, thus making them feel like they have lost their "home". In both cases of Nevatia and Shormistha, there is a loss of authority. They are unable to express themselves and it is either the physician or their illness that 'speaks' for them. Furthermore, there is little importance given to their emotional state. Although Shormistha does get sympathy of the doctors, they can never understand her inner turmoil as they generalize the victim's emotions based on how other such patients reacted in the past. This is where illness narratives play an important role. They offer a chance to the victims to regain the control of those episodes and phases as they write about their past. These narratives record that phase in the lives of the victims when they lose authority over their own actions. The process of narration gives them a voice and a control through language, which further helps in their process of healing. Language gives the writer control, as one can observe after analyzing the two chosen narratives for the study. "But it is invariably language that helps you establish an identity" (483) writes Nevatia in his memoir.

Even after recovery, the victims of illness cannot immediately return to their old selves. Illness changes people and makes them unrecognizable. But through illness narratives the victims can express their flaws and their episodes- it becomes a way to purge themselves of their past trauma of suffering and move on. Some form of control is what they can regain through their narratives. On the other hand, readers, who might be suffering from the same dilemmas, are able to create their own meaning and arrive at a sense of peace and catharsis after reading the narratives. Thus, illness narratives offer a healing space, not only for the victim but also for the reader. The author and the reader are on two opposite sides of the book and end up creating a new hybrid meaning.

Not only healing, illness narratives also assign an ethical responsibility to the readers. When a reader reads an illness narrative, they should make it their priority to be open minded and listen to what the author is trying to express. Rather than jumping to conclusions or being judgmental, they should concentrate on their own experience of reading the tale of suffering. Instead of questioning the validity of the experience, the reader should first try to focus on how the book has affected them and helped in the process of their own healing. Readers might begin to admire the writer or take them as their role model. Readers should keep in mind their ethical responsibility to concentrate and introspect on their own experience of healing from reading the narrative more than anything.

CONCLUSION

Literary works on illness, or in other words, illness narratives are thus crucial in understanding and evaluating the lives of the patients. As has been established in the discipline of narrative medicine, in the treatment of the chronically ill, it is important to understand and integrate the patients' stories of their illness. Not only it bridges the gap between the patient and the healer and makes the healing more effective, it also helps the patients find meaning to their life. While the field of narrative medicine and the study of illness narratives have increased for obtaining healing benefits, it should be noted that it is not a new practice. Narrative medicine adds a human aspect to the clinical process and the everyday lived experiences of the patients indirectly improve the patient health care.

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