Beyond Pathology: Illness Narratives in Indian English Literature

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Abstract

Highly advanced technological tools and skills improved the technical progress in the field of medicine but the feelings of dissatisfaction from the treatment, distance and lack of attention from the doctor, dismissed empathy and understanding makes the treatment seem completely technical for the patient, eliminating core elements like trustworthiness, empathy and sensitivity. Because of their undisturbed focus only on the disease as well as stiffness caused by their medical training, doctors fail to listen and connect with their patient's struggles pushing back human emotions. Illness Narratives play a huge role in humanizing the medicine, helping doctors to practice with empathy, understanding and sensitivity towards their patients, widening their narrow focus from biological disease only. Illness Narratives also reveal the evils and stigmas attached to various diseases, limitations of medical profession, cultural and

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familial influence as well as psychological and emotional sides. The paper will attempt to explore a memoir, *Healed: How Cancer Gave Me a New Life* by Manisha Koirala and Neelam Kumar to understand the importance and significance of illness narratives in Indian context. The paper also aims to explore various practical implications of illness narratives.

Keywords: Illness narratives, Empathy, Memoir, Medicine.

Objectives

1. To understand the concept of illness narratives.
2. To examine the importance and significance of illness narratives in the Indian context.
3. To analyze the practical implications of Illness Narratives.

Methodology

The paper is based on qualitative analysis and is purely theoretical. The primary texts include non-fiction memoir: *Healed: How Cancer Gave Me a New Life* by Manisha Koirala and Neelam Kumar and the secondary texts include *The Illness Narratives: Suffering, Healing, and the Human Condition.* by Arthur Kleinman, *Narrative Medicine: Honoring the Stories of Illness* by Rita Charon and *The Wounded Storyteller: Body, Illness, and Ethics.* by Arthur W. Frank, and *Illness as Metaphor*by Susan Sontag.

Illness Narratives either refers to oral narrations in everyday life with friends, family or the biographical and autobiographical writings that articulates experiences about an illness and suffering. Illness narratives help in better understanding of illness and to construct meaning in chaos. Illness narratives can be both written by a patient, care-giver, or medical professionals. Illness Narratives means narratives depicting illness that give insight into patient's life that medical data can never. Illness Narratives are usually written in first person narration and can take many forms such as art, fiction, non-fiction, film etc.

Arthur Kleinman in his book *The Illness Narratives; Suffering, Healing and the Human Condition* says, "The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering" (64). Illness Narratives talk about a patient's illness, sufferings, struggles, drastic changes caused by illness and patient's resilience to find meaning in illness.

Frank in his book *The Wounded Storyteller: Body, Illness, and Ethics* states, "Patients become storytellers, using narratives to reclaim agency from disease" (55). Narratives of illness can serve as a tool that bridges the communication gap between doctor and patient, making it easier for the doctor to understand the condition of the patient and helping him to develop a more empathetic attitude. Rita Charon observes in *Narrative Medicine: Honoring the Stories of Illness* that a medicine that does not engage "authentically and profoundly with patients' experiences" might still achieve technically what it sets out to do. But as she notes, "such a medicine will be an unsatisfying one, or at best only half a full medicine" (6).

Illness Narratives revolutionized medicine and its practice. Illness Narratives narrate the lived experiences of illness and suffering. There is a vast amount of literature in the Western world about the illness experience. Much less has been documented about this in India. Stories that show how medicine is shaped by family and cultural forces, and which bring a psychological perspective to the patient's experience of being unwell. Moreover, they highlight the limitations of the medical system in India.The fact of the matter is, being unwell is not about one's physical condition in India, but also a host of factors surrounding it.

***Healed: How Cancer Gave Me a New Life* by Manisha Koirala and Neelam Kumar**

Healed: How Cancer Gave Me a New Life is an Indian non-fiction cancer memoir of Manisha Koirala and Neelam Kumar, originally published in 2018. It is an Illness narrative of third-stage ovarian cancer survivor who narrated her struggles, sufferings and journey of illness in this book. The analytical reading of this book discloses the stigma attached to cancer, dependence on rituals and superstitions, the familial support as well as pressure, the dismissed autonomy of patients, emotional and psychological dimensions as well as limitations of doctors and medical system.

For delivering a new and difficult diagnosis to a patient, a doctor must be clear, empathetic and honest in his speech. He must deliver it with understanding and empathy, keeping a balance between facts and emotions. He is also supposed to tailor his speech according to patient's emotional state and level of understanding. The book *Healed: How Cancer Gave Me a New Life* by Manisha Koirala reveals the limitations of medical doctors. In the book, the doctor's speech while explaining the diagnosis was clinical and emotionally detached. Doctor failed to provide a clear explanation with empathy and spoke imprecisely. The book reveals a communication gap between the doctor and the patient. Manisha Koirala in her book states:

> 'Manisha, there are treatments for these things nowadays'. 'Treatment? What do you mean by treatment?' I yelped. I was agitated, pulling at my brown neck scarf impatiently. It suddenly felt as if it were constricting me. 'It's not like earlier. Science has advanced a lot. There are various effective treatments. People do live longer.' 'But what do I have? What treatment are we discussing?.' (14)

The doctor's ineffective and mechanical communication, vague phrasing and emotional hollowness evoked restlessness, fear and anxiety in patient's mind. The doctor's statement, "Science has advanced a lot. There are various effective treatments. People do live longer" exposes the stigma and fear attached to cancer. In her book, Manisha states, "My verdict has been pronounced. Cancer had won. I was dying." (10). This line too reveals the stigma attached to cancer treating it as unbeatable disease, equal to death. Cancer is proportioned to death. The World Health Organization defined Stigma as "hidden burden of disease" having psychological, physical, and social consequences (2001). Susan Sontag speaks about harmful stigmas attached to diseases like Cancer and TB in her book *Illness as Metaphor*. She mentioned:

> Two diseases have been spectacularly, and similarly, encumbered by the trappings of metaphor: tuberculosis and cancer. The fantasies inspired by TB in the last century, by cancer now, are responses to a disease thought to be intractable and capricious - that is, disease no understood - in an era in which medicine's central premise is, by definition, mysterious…..TB was thought to be an insidious, implacable theft of a life. Now it is cancer's turn to be the disease that doesn't knock before it enters, cancer that fills the role of illness experience as a ruthless, secret invasion - a role it will keep until, one day, its etiology becomes as clear and its treatment as effective as those of TB have become. (5)

This extract from Susan's book reflects how few diseases like TB and cancer instead of being treated solely as medical conditions are viewed and stigmatized as ruthless, secret invasion, or theft of life. People's perception of diseases is stigmatized and culturally shaped.

The Illness narrative of Manisha also reveals her emotional and psychological world. Right after being diagnosed with third stage ovarian cancer, her world collapsed. In her book, she states, "But I was in a state in which my mind refused to comprehend anything. I am not sure I heard anything after that. The room was spinning. The ground had slipped from under me. I was at once floating and sinking. It was a strange space to be in". (15) This reveals her physical and emotional incapacity to comprehend anything.

Manisha's book *Healed: How Cancer Gave Me a New Life* puts forward the ambivalent role of family in Indian context. Their presence and care reveal their supportive role whereas their full control over patient's decisions and over involvement reveals their role as a pressure. The loss of autonomy and agency creates frustration in the mind of the patient. Manisha states, "I had overheard the family's plans, first at the hospital, then at my family home. They were planning to fly me to Mumbai for a second opinion. At this point I had no say in the matter. No protests to make. I was just an automation, going with the flow. I felt sorry for myself" (16). This line highlights the loss of patient's autonomy in making decisions related to her illness. In western settings, the power of making decisions related to illness resides in patient's hands but in Indian settings it shifts towards the hands of family members. But Family plays a very great role in providing care, emotional strength and help to the patient. In her book, she writes:

> I have no idea how the hours after that were spent. I kept staring at the wall. But one by one, my family members came up to me. Silence lay between us like an impenetrable bridge. Gently, they placed their arms on me and then faded into the background. No words were spoken, just a compassionate touch to know they were there. It was the longest and loneliest night I have ever spent. (Koirala 15)

The presence of family acts as a strength for the patient. This reveals the positive role of family. Even though her family surrounded her, she felt lonely. The statement "It was the longest and loneliest night I have ever spent" reveals that an illness is purely an individual experience.

Arthur W. Frank in his book, *The Wounded Storyteller: Body, Illness, and Ethics.* explain three forms of illness narratives. First is restitution narratives, secondly chaos narratives and last quest narratives. Chaos narratives are truly real as they reflect the chaos within patient's mind, the plot is not linear and the speech fragmented. In chaos narratives, there is sense of loss and being trapped by an illness. In her book Koirala says, "If this is the end of my life. I must accept it, Yulia.' I whispered" (17). She also states, "It had been by launch pad to make plans for my wondrous life ahead. Overnight, things had changed. I was no longer in a position to make plans; I had no life to live. I felt spent" (16).

After diagnosis, Manisha life changed overnight, leaving her pessimist about her life. The phrase "I had no life to live" is the explanation for the troubled and emotional state of affairs. This illness narrative also reveals the personal beliefs. Manisha's family had given up on the idea of modern medicine and instead believed in the efficacy of astrology and rituals in fighting cancer. In the book she stated:

> I learnt later that my cousins had rushed to an astrologer on hearing the doctor’s verdict and consulted him about my Vedic astrological chart. To their amazement, the astrologer had predicted that this person, whose name they had hidden from him, will have to be hospitalized for the treatment of cancer. My cousins were speechless. And then they asked, ‘Is there a way we can save her? She is our cousin Manisha Koirala’. The learned man advised that they immediately perform the Mahamrityunjaya puja or the death conquering ceremony followed by havan. (Koirala 18)

It reveals dependence on non-scientific practices and personal beliefs. Illness Narratives helps to understand the psyche of the patient and various sociocultural factors playing their part in it. It helps to recognize and reevaluate the limitations among medical fraternity. It helps to recognize and reevaluate the limitations among medical fraternity. Illness Narratives shed light on the challenges that patients face during the period of diagnosis, management and rehabilitation of their illness. It reveals the emotional and psychological dimensions of a patient.

Stories about disease can be considered as emotional narratives of disease. As emotional narratives of disease, they are not there to be read, but to be dissected. When doctors truly listen to what is going on in a patient’s life, they gain valuable insight into what is occurring within the body and the impact the illness is having on the individual. Many patients indicate that this if every patient could share their experience of being treated as a ‘case’ rather than a person they might have a very different view of their local hospital.

Doctors can use this insight to improve the way they communicate, to be more compassionate and to really hear what their patients are going through. So that they can look after patients and families in a better way and to a better standard, and to improve the care experience for all. The practice of medicine is becoming increasingly more technical and disease oriented. In this, the emotional and psychological impact of disease is neglected. Illness Narratives uncovers patient's authentic reactions to the diagnosis. The purpose of the drug is to facilitate the delivery of care for other diseases for which curative interventions may be required. Studies in Illness Narratives show the psychological state of the patient and that of his family while he is afflicted with an illness.A patient with physical disease also has to go through mental depression, anxiety, fear of death etc. A doctor with the help of these narratives must encourage mental counselling along with physical treatment and must adopt effective measures to lessen the impact of disease on their psyche.

Illness narratives expose stigmas attached to various diseases such as Cancer, TB, AIDS/HIV etc. This world needs to be changed using illness narratives, so that diseases are not stigmatized. Through illness narratives we can see how the patients lose their autonomy and decision-making capacity. Although it is important for the families to carry on giving the love and care they have always given, it is also very important for the patient to have a word to say. If the patient feels that they are not given autonomy or decision-making capacity it could negatively affect the patient's recovery. Through a close reading of illness narratives there are advantages that can be derived for other patients. So that the patients feel less lonely with their sickness and are understood. These texts become a source of hope and inspiration for them and also encourages them to write and express their own journey. Illness narratives can also help government to formulate right healthcare and education policies. Arthur Kleinman in his book *Illness Narratives; Suffering, Healing and the Human condition* stated:

> The only effective reform, to my mind, would be to restructure the medical training program from bottom to top. Short of that, values and behaviour will not change. Time must be devoted in the curriculum to teaching students how to interpret the illness narrative and assess the illness experience. Courses in the medical social sciences and humanities are a beginning, but we also need new ways of teaching about doctor patient transactions and supervising the clinical experiences of medical students. (267)

Kleinman focused on making knowledge of illness narratives inclusive to medical training programs. Illness narratives can help in developing equitable and ethical practices in medical system and healthcare. He also states, “Narrative competence permits caregivers to fathom what their patients go through, to attain their illuminated grasp of another’s experiences that provides them with diagnostic accuracy and therapeutic direction” (30). Illness Narratives reconnects the patient to his self and to the doctor. To doctors, it provides assistance to develop empathy, understanding and better communication skills.

Conclusion

Arthur Kleinman described illness as a lived experience. So, Illness narrative is a narration about those lived experiences that takes into account the physical, psychological, emotional, mental, social, and cultural world of the patient. The paper aims at eliciting the relevance of illness narratives in India and in this context examining the limitations of the health care system, the social stigma associated with various diseases and the cultural and familial roles and doctor-patient relationships. In recent years there has been a shift in focus in the health care sector and this shift has contributed to a redefinition of the relations between medicine and society. For a long time, medicine as a technical enterprise has been the focus and the patient's experience has been relegated to the margins. It was only with the emergence of the postmodern perspective in the 1970s that the genre of illness narratives made its entry. Since then, many patients have started narrating their illness experiences and, in the process, articulating their social and cultural worlds. In this context illness narratives emerge as a unique form of health care experience. Through illness narratives patients can reconstitute themselves and lead a more fulfilling life. Narrating about their illnesses, patients can acquire a new self-definition. Narratives about illness also serve a therapeutic role for the patients in coping with their illness experiences. Narratives about illness provide immense knowledge about the human condition and the ways in which humans cope with illnesses and injuries. In this sense the study of illness narratives is an area of research that has the potential to revolutionise health care practices and make them more patient-focused and humane.

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