



# Restoring the Patient's Voice- Narrative Medicine and the Re-Humanization of Cancer Care: A Study With Special Reference to the Empirical Gap Identified in *The Emperor of All Maladies*

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## Abstract

Siddhartha Mukherjee's *The Emperor of All Maladies* is a much-celebrated work on the "biography of cancer". It traces the historical, scientific, and social evolution of humanity's battle against one of the deadliest diseases. Despite its meticulous chronicling of the ongoing oncological advances and scientific rivalries, the text accentuates a striking gap in the relative scarcity of patient-centered narratives in the historiography and practice of cancer therapy. Cancer, in the novel, is profusely narrated as a biological and institutional story, that quite often reduces its patients to docile and inactive subjects of biomedical intervention rather than active narrators of their own lived experiences. This research paper examines this omission as a critical and a predominant research gap and positions it within the domain of Health Humanities that stresses upon the amalgamation of literature, ethics, oral narratives and history to humanize clinical practice. This paper argues for a paradigm shift to reframe the outlook on cancer: from treating cancer as a biological battle to understanding it as a lived human experience.

**Keywords:** illness narratives, marginalize, medical discourse, medical gaze, objectification

## Introduction

Health Humanities as a field emerged to emphasize the importance of art, philosophy, literature and history in understanding health and illness. Within this vast domain, narrative medicine ought to have restored, analyzed, reflected and empathized with patients' illness and stress associated with it. During early modern period, diseases were conceptualized based on Humoral theory that mirrored illness as a potential imbalance existent within the human body. Foucault redefined patient's role, emphasizing how they were merely reduced to bodies for examination. The patient's emotional appeal and stories of hardships were regarded as entities of least importance when compared to the physician's diagnosis. By the early

20th century, cancer care encompassed a wide range of treatment procedures that almost represented a biological riddle to be solved. The procedures included surgery, chemotherapy, radiations and palliative care that were very crucial and much unknown to the world.

Narratives on illness, articulate a patient's personal suffering and journey through illness, thereby promoting empathy and understanding of a diseased human condition. These narratives are highly subjective and provide space for representations on illness across different cultures and societies. They indeed humanize the experience of illness and possess the ability to offer profound knowledge on how illness can transform a person's



life and identity. The term narrative medicine was first coined by Rita Charon in the early 2000's that defines narrative medicine as "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness." It postulates physicians to actively listen, meaningfully interpret and co-construct patient's illness narratives. Cancer is well-suited along with narrative medicine because of its prolonged trail, existential hazard and the identity altering-impact it can have on a person. Unlike other acute illnesses, the journey of a cancer patient unfolds over months or years, undoubtedly creating a need for sustained narrative engagement. Audre Lorde's "The Cancer Journals", stand as a classic example for Illness Memoirs, which foregrounds issues related to gender, race and identity in breast cancer experiences.

Through an active study of historical medical discourse, the paper illustrates how tumors have shaped the ongoing oncological practice. The paper also highlights on how narrative medicine and illness memoirs can help reacquaint with the patient's voice. This potent methodology not only helps in enriching medical knowledge but also help boost effectiveness in the treatment procedures through communication, empathy, and shared or collaborative decision-making. The paper proposes an innovative framework to incorporate patient narratives into oncology, which would include digital storytelling platforms for patients, narrative-based training for oncologists, and AI-assisted inspection of illness narratives to discover the psychosocial needs. Examples are drawn from cancer memoirs, various literary representations of this serious illness, and emerging advancements pertaining to this disease in the medical field.

When The Emperor of All Maladies: A Biography of Cancer by Siddhartha Mukherjee was published in 2010, he offered readers an extensive chronicle of humanity's historical struggle against cancer. The book won the Pulitzer Prize and was hailed for extending the reach of science to a wider audience. Through the lens of biography, cancer is portrayed as a much dominant and a challenging adversary that has shaped the trajectory of medical research and innovation.

The book acknowledged the massive suffering endured by the cancer patients, and to a great

extent remained pensive with the formulations of researchers, physicians and policy-makers. The patients are generally used merely as data for case studies and statistics, unmindful of the stories they ought to reveal. It vividly prioritizes and privileges the disease, rather than the carrier of the disease. This is definitely a striking as well as an unsettling issue that reflects a deeply ingrained epistemological bias that tends to exist in modern medicine. Patients are rarely seen as the champion of their own stories.

Michael Foucault worked on the archeological and genealogical analysis of the medical discipline and its various processes, trying to shed light on the 'episteme' that characterized medical knowledge and discourse. He records the concept of "Medical Gaze" in his *The Birth of the Clinic* as,

*"The clinical gaze is not an innocent, purely objective view but is shaped by specific historical, social, and cultural forces that create its "truth. It emphasizes how the professional medical perspective can create a gulf between the patient's subjective experience and the physician's objective diagnosis and treatment. The gaze separates the "sickness" from the person, leading to a view of the sick person as a "collection of synchronized organs" rather than a fully integrated human being. The clinical gaze isn't neutral; it's an exercise of medical power, supported by a specific body of knowledge that constructs the patient as an "object" of study."*

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In the study of cancer, this objectification is particularly grave and serious. The absence of patient-centered narratives can at times be very hazardous. This is very crucial as it shapes how medical histories are written and how this dreadful disease gets culturally represented. The Patients' oral narratives on their discomfort, depression, anxiety, fear, resilience, image transformation, loss of identity, isolation, and trauma remain regions underexplored. This gap existent in the book needs to be bridged in order to humanize healthcare. However the central argument would continue to remain in integrating and restoring the unheard voice of the patient, not merely as an element of compassion but as a pathbreaking innovation in cancer care. This would significantly affect in reshaping medical education, its policies and practices.



The history of cancer treatment, as expressed in *The Emperor of All Maladies*, straightens itself as a chronicle of scientific experimentation, institutional rivalry, and technological progress. Right from the surgeries performed by William Halsted in the late 19th century to the modern “magic bullets” of chemotherapy in the 20th century, the story grants a special right and immunity to the so called “scientist-hero” and the trends in the technological advancements. Very uprightly the narratives reflect the well-established patterns of treatment that has been very evidently privileging the practice over experiential accounts. The text also provides answers to man’s quest for improved treatments and understanding of cancer. Mukherjee, himself being a scientist and oncologist very meticulously reveals the personalities of the patients (including children) and the scientists involved.

Mukherjee’s very brilliantly exemplifies the idea of what is done to the tumor cells in medical domain rather than what the human experience associated with it can reveal. There is definitely a need to address this biomedical tendency to objectify and marginalize a patient. Systematic neglect of cancer affected patient’s narratives is highly prevalent in the history of cancer medicine. While there is a very high propaganda about the scientific advancements in the treatment of cancer, the voices of the affected remains muted.

This is because in the field of medicine, focus generally shifts towards doctors, diagnosis and diseases. This probably can lead to distorted narratives, where the patient gets sidelined. Their stories are often reduced to symptoms and side effects. Indeed their narratives are rich with identity crisis, constant fear of recurrence, transformed body images that provide a wide array of existential reflections. It is very sad that these power-packed narratives in no way get integrated with their treatment procedures. Their stories of battle and survival are self-explanatory, revealing the complexity, struggle and acceptance that comes with it. This neglect is not trivial. Research throws light on how the ability of the healthcare providers to listen and interpret patient’s stories, can have a very direct impact on the patient’s health. This is because of its capacity to improve empathy, diagnostic accuracy

and adherence to a particular way of treatment. It also results in a personalized model of care catered according to the needs of the patients.

This research paper helps to build on the research gap identified in *The Emperor of All Maladies*, and proposes an innovative framework to integrate patient narratives into the practice of oncology through three different strategies:

1. **Training on Patients’ Narratives for Oncologists:** This method will involve the incorporation of narrative medicine into medical curriculum and more specifically into oncology studies. Oncologists should be given training not only in identifying the staging tumors but also in identifying their patients’ stories of battle against the dreadful disease.
2. **Creation of Digital Storytelling Platforms:** Through this method, secure digital platforms can be created for the cancer patients where they can very effectively record, share, and archive their illness narratives. These stories possess the ability to offer deep insights into psychosocial needs that often remain invisible in quantitative studies. In a way narratives can inform and transform medical research and clinical practice.
3. **AI-Powered Narrative Analysis:** This method marks a fusion of humanities and technology for a well structured patient-centered care. Here natural language processing (NLP) tools are primarily used to analyze large corpora of patient narratives. These tools are capable of identifying the recurrent themes, (such as fear, hope, stigma) effectively detect linguistic markers of stress or anxiety, and offer physicians with real-time insights into patients’ psychosocial well-being.

Though narrative medicine is highly therapeutic, it acknowledges patients as narrators, and resists their objectification commonly inherent in medical discourse. It gives the patients’ a potential to define what cancer means to them rather than being defined solely by clinical and scientific categories.

## Conclusion

Though *The Emperor of All Maladies* very constructively narrates the history of cancer, it lacks the intrusion and inclusion of “the patient’s voice” in its narrative. This research paper has argued that this



omission reflects a broader gap evident in the field of oncology. By integrating AI-assisted analysis into oncology, digital storytelling platforms and narrative training to physicians, cancer care can move beyond tumors and survival curves. In doing so, cancer can never be seen as a biological adversary but as a shared human-story, which the society on the whole co-narrate together.

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