

Beyond the Clinic: Exploring Illness Memoirs Through Medical Humanities

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Abstract

Medical humanities, an interdisciplinary field, analyzes illness narratives to study the representation of disease, medicine and medical professionals. Among the illness memoirs, the patient as well as the doctor narratives became popular, as majority of the readers experienced a therapeutic relief of their hidden fears related with disease and death. The victory of modern medicine, challenges faced by the medical professionals and the doctor-patient relationship are the main themes of medical memoirs. The present study focuses on the doctor memoirs and it tries to study how far bioethical concepts have influenced the depiction of medical experience by doctors.

Keywords: Life writing, illness narratives, memoirs, medical humanities, pathography, bioethics.

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INTRODUCTION

“Pathography is an immensely rich reservoir of the metaphors and models that surround illness in contemporary culture. These books are of value to us not because they record “what happened” –for they are not, as we have seen, factual accounts – but precisely because they are interpretations of experience.” Anne Hunsaker Hawkins in her famous work, *Reconstructing Illness* states that, the distinguishable feature of the pathography is, its interpretation of experience through story telling. It is not possible to comprehend the feelings of the medical professionals and patients from their medical notes. Clinical notes are prosaic and factual in nature. Patient memoirs contain the description of illness experience. Doctors get the opportunity to express their emotional reactions to clinical situations in a non-clinical language through memoirs. While writing their memoirs, doctors can express themselves clearly and are not confined by the strict rules of their medical profession.

R S, Downie and Jane Macnaughton states in their work, *Bioethics and the Humanities: Attitudes and Perceptions*, the tendency in doctors to demonstrate supererogation. “Doctors not infrequently see themselves as acting in a supererogatory manner. Perhaps they might be better doctors if they were able to come across to their patients as balanced human beings, rather than as supererogatory martyrs” [14]. The urge to exhibit professional competence and the fervent belief of patients as well as their care givers on the healing power of modern medicine force doctors to behave

indifferently. Majority of doctors prefer to remain aloof and focus only on the curing of a disease. Moral obligation and altruism exhibited by medical professionals are subjective.

Some of the illness memoirs included in the study are, *When Breath Becomes Air* by Paul Kalanithi, *The Emperor of All Maladies* by Dr. Siddhartha Mukherjee, *Jeevitham Enna Divyanubhavam* and *Jeevithakkazhchakal* by Dr. V P Gangadharan, American surgeon Dr. Atul Gawande’s book, *Better, Being Mortal* and *When the Air Hits Your Brain* by Dr. Frank Vertosick. While narrating their personal journey and professional experience, some memoirists might exaggerate or overemphasize the facts related with their illness experience and this could aid in creating misconceptions and hypes. The selected illness narratives are analyzed from the perspective of medical humanities.

Medical humanities as a discipline took shape in the late 1960s and in the early 1970s. As a discourse, medical humanities emerged in response to the insensitivity and profit motive that have been ruling medical and health care field, all the times. Literature and arts offer a rich medium for teaching ethics. The interdisciplinary nature of medical humanities thus, helps in inculcating humane values, by changing the tendency to see patients as mere bodies afflicted with disease. Medical humanities tends to focus not on the practical resolution of ethical problems, but on their

cultural and historical contexts, emotional and existential dimensions, literary and artistic representations. Bioethics emerged as a field alongside medical humanities and was perhaps indistinguishable from it at first. Medical humanities addresses several ethical problems addressed by bioethics and in some ways overlap with bioethics. Both are similar in certain respects [R Cole, 2]. The domain of bioethics primarily addresses issues like patient consent, physician- patient relations and medical ethics.

The Stories Doctors Tell

Jeevitham Enna Divyanubhavam and *Jeevithakkazhchakal* are popular autobiographical narratives by the famous oncologist Dr. V P Gangadharan. In, *Jeevitham Enna Divyanubhavam*, Dr. Gangadharan shares his experience as a doctor, his outlook towards the medical profession and human life. Dr. Gangadharan cautions the readers about the prevalence of fake healing practices in cancer treatment. According to the author, the character of people afflicted with a chronic disease often undergoes, a huge transformation. The Doctor opines that, all human beings should experience chronic diseases like cancer to understand the value of love and compassion [35]. Dr Gangadharan's statement could possibly evoke, the pre-modern view of the connection between a person's disease and character. In the Doctor's view, self-centered people, would understand the value of feelings only when they become chronically ill. Susan Sontag, in her work *Illness as Metaphor* observes that, "With the modern diseases [once TB, now cancer], the romantic idea that the disease expresses the character is invariably extended to assert that the character cause the disease—because it has not expressed itself. Passion moves inward, striking and blighting the deepest cellular recesses" [Sontag, 46]. Despite the advancements of modern society, many people tend to believe that, disease and disability are the results of one's sin and evil character. This prejudice against the chronically ill and the disabled people gets mirrored in the objectionable and insensitive dialogues of some popular movies.

In Dr. Gangadharan's view, giving overemphasis to medical reports and ignoring the patients' experience and the narration of their disease, will never give a proper clinical judgement. He further mentions that, it is cruel and insensitive to approach a terminally ill patient with the application forms. In his view, our society and family play a considerable role in the withdrawal tendency shown by cancer patients. Expressing pity and giving unsolicited advice often force cancer patients to withdraw from normal life. Films also play a main role in propagating hypes and inflated facts related with cancer. The author implicates that medical professionals should maintain a warm relation with patients to understand them. In doctor's opinion, robotic treatments could never replace a doctor's healing words and genuine compassion. A doctor's inability to empathize with the patients' lived experience creates a

breakdown in communication between them. Though not directly mentioned in his memoirs, Dr. Gangadharan stresses on the importance of the idea of 'narrative medicine', the concept proposed by Dr. Rita Charon in 2000. She mentions in her work, *Narrative Medicine: Honoring Stories of Illness* that, close reading of literature and reflective writing helps to have an effective understanding of narrative situations in medicine.

In *Jeevithakkazhchakal*, Dr. Gangadharan expresses his abhorrence towards, the image of crab connected with cancer. From his perspective, the image of crab incites and maintains the horrifying image of cancer. Instead of this distressing image, Doctor suggests images like flower or smiley to create hope and the desire for survival in cancer patients [25]. Many private hospitals, with their corporate attitude, exploit the miserable condition of the poor patients. As stated by the doctor, numbering patients instead of addressing them by their names is an inhumane tendency. Along with the discussion of patient's rights and informed consent, Dr. Gangadharan also shares instances where patients and their care givers expect medical professionals to act in supererogatory manner, exceeding the requirements of duty. The pressure to maintain the savior's image often force medical professionals to work neglecting their own physical and emotional well-being.

In his book, *Better* Dr. Atul Gawande argues that, just like in any other profession, medical professionals must confront and address the shortcomings within their field. He elaborates on the cases where his diagnostic error worsened the patients' health condition. Gawande admits that, medical negligence happen due to the inexperience of doctors. He also, points to the limitations of modern medical science. In his opinion, majority of the patients prefer death over life-extending treatments and procedures. From his perspective, a significant number of his patients chose hospice care due to their fear of longevity- enhancing treatments. Many patients were not willing to endure the hardships that accompanied such treatments. In this matter, the consent of the chronically ill is not asked. Dr. Gawande similarly remarks that, people become skeptical when they see increased income of doctors [Better, 113-114]. Writing gives doctors an opportunity to reflect upon their decisions. [256]. Through the act of memoir writing, doctors get the chance to interact with the society and discuss the critical situations that force a doctor to take risks. Through his works, Dr. Gawande points that, like any other profession, doctoring too is not free from laxness. The author admits that, medical mishaps occur when the medical professionals behave negligently.

Dr. Vertosick in his work *When the Air Hits Your Brain* states that, the power given by medicine to doctors and the dominance provided by it, to violate another human being's privacy is intoxicating [Vertosick,37]. In his view, popular medical dramas use

cardiac arrest as a troupe to attract viewers [Vertosick, 39].] Dr. Arthur Frank, in his work, *The Wounded Story Teller* shares the same view. “Popular culture often plays one image against the other, idealizing health in contrast to illness, and depicting illness as pitiful in contrast to idealized health” [Frank,45]. Increasing life style diseases in the society has made people health conscious and this has also increased the apprehension over health issues. People prefer to have a cleaner contact with any disease and reading illness memoirs ensures this [Glasser,2]. It is a natural tendency in human beings to derive voyeuristic pleasure from other people’s lives. As illness involve stages like suffering and healing, people get relief from watching/ reading illness narratives in films and books.

Vertosick feels that, his profession and its heroic image often normalize rude and mean behavior with patients. [79-80]. Doctor compares doctors with politicians, because they stress only the good things about a patients’ medical condition. While dealing with the critically ill patients in certain circumstances, doctors forget to behave benignly. John K Crellin states:

The question seems a reasonable one if we watch a lot of TV medical dramas, as they focus on dramatic medical events that require immediate technological competence, often by professionals who are insensitive and rude, inept as members of a team, and dysfunctional in their personal lives. That they were smart and highly competent in their scientific medicine seemed to excuse their generally unpleasant behavior. [7]

Guilt torments Dr. Vertosick when he fails to save a patient named Charles. His guilt makes him compare himself with Raskolnikov, the protagonist of *Crime and Punishment* [174-175]. Vertosick’s friend Dr. Gary advises him not to become an ideal doctor, when Vertosick refuses to conduct surgeries for fear of failure. His fear of failure almost brings a vocational crisis in his profession. Dr. Gary comforts him and compares neurosurgery to, ‘the land of nightmares’. He also reminds Vertosick not to get emotionally involved in his cases as medical ethics forbade medical professionals from having any kind of emotional attachment with patients. This could make doctors nervous while performing surgeries [176-178].

Dr. Vertosick recollects in his book some occasions where doctors refuse to take independent decision and choose advanced treatments like radiation and particular surgeries fearing legal trials. Here, the author expresses dilemmas faced by medical professionals. They will have to face litigation, if their decision to choose some medical procedures for a patient goes wrong. The author’s colleague, Dr. Sakren addresses lawyers as “Goddamned lawyers” as he feels that, lawyers cause more harm and create unwanted complications without understanding the professional

issues of neurosurgeons. [187-189]. Emily Dickinson in her poem, *Surgeons must be very careful* wrote that,

“Surgeons must be very careful
When they take their knife!
Underneath their fine incisions
Stirs the Culprit—Life!”

Surgeons need to be very cautious while performing surgeries because, beneath it, there lies the culprit, life. As indicated by Emily Dickinson in her poem, doctors need to become extremely vigilant while taking decisions related with a person’s life. At the end of the book, Dr. Vertosick gets afflicted with parkinson’s disease and this make him unfit to conduct surgeries. Doctor learns the fact that his status as a healer is turned into that of a patient and this experience changes his attitude towards his patients.

Dr. Siddhartha Mukherjee begins his work, *The Emperor of All Maladies* with the proclamation that, his book is a history of cancer. Doctor elaborates on the history of cancer treatment, research, and his experience as an oncologist. In his opinion, metaphorical seductions of a disease like cancer are justifiable. With this statement, the writer seems to defend the metaphors that intensify the frightening image of cancer. According to the doctor, to name an illness is to describe suffering. In his words, “medicine, [I said,] begins with storytelling. Patients tell stories to describe illness; doctors tell stories to understand it. Science tells its own story to explain diseases.” The narrative of a doctor is entirely different from a patient’s version of it. Because, a person afflicted with cancer becomes a story teller first, the narrator of suffering, before becoming the subject of medical treatment [46]. Here, the author stresses on the key role played by narratives in the field of medicine. Anne Hunsaker Hawkins notes in her work, *Reconstructing Illness: Studies In Pathography* that, the pathographies became common only after the 1950s and, the publication of illness memoir was rare before the 1900s. [Hawkins, 3]. Doctor says that tobacco lobby tried every possible way to hide from the US citizens, scientifically proven facts connected with cancer and cigarette smoking. In his opinion, it is easy to fan anxieties about cancer.

James Kyung-Jin lee in his recent work, *The Pedagogies of Woundedness* observes that compared with the physician’s narratives, the narratives by patients give an authentic account of the disease experience. In physician’s narratives, doctors remain principal agents. “[for] illness narratives, stories told by people with and about their illnesses, stories told through their ill, wounded bodies can represent- as no physician’s memoir can- just how disruptive and transformative illness is to the person who experiences it [16].” Undoubtedly, an objective account of a chronic illness, irrespective of the status of the author, up to a certain extent can help in removing stigmas and hypes related with disease.

Dr. Paul Kalanithi, an American neurosurgeon begins his memoir *When Breath Becomes Air*, by disclosing the details of his cancer diagnosis. His status as a doctor soon changes to that of a lung cancer patient. He handles the situation without losing his composure. His hectic work schedule induces him to believe that, he failed to realize the worth of human significance in his profession and has become a regular and stereotypical doctor [85]. Paul strives very hard to become an ideal doctor and it causes him great distress, when he feels that he has not achieved it. He also realizes that when afflicted with chronic illness, a person's values constantly change. "As a doctor, I was an agent, a cause; as a patient, I was merely something to which things happened" [142]. Paul learns how patients feel, when important decisions regarding their disease and health is taken, without their consent. Paul's ego as an efficient doctor gets hurt, when a resident doctor describes the side effects of a medicine. Here Paul realizes what happens when the medical professionals misapprehend the sentiments of their patients.

Clinical encounters with mortality

James Kyung-Jin Lee, mentions in his work *Pedagogies of Woundedness* that, the inevitable deaths of patients confront doctors as vocational crisis. Dr. Vertosick in his book, *When the Air Hits Your Brain* shares his experience, where the death of a patient shatters his confidence and makes it difficult for him to perform surgeries. In Dr. Atul Gawande's view, doctors feel threatened when the modern medicine and technology fail to save their chronically ill patients. [15-16]. Doctor Atul Gawande, in his work, *Being Mortal* mentions about the nightmares that haunted him. In his dream, he saw the corpses of his patients lying on his bed. This happened mostly during the initial phase of his medical career. [17]. Later, Dr. Atul's medical experience changes his initial difficulties, and he realises that, one needs to have the courage to confront the reality of mortality. In his work *Better*, Gawande expresses his dissension against the use of medical procedure for capital punishment. He feels that, by using the medical technology for executing people, governments are manipulating and violating medical ethics. Atul stresses on the importance of hospice care and states through his works that, terminally ill patients have the right to decide whether to continue their life prolonging treatments or choose the end-of-life care.

In Dr. Paul Kalanithi's opinion, the first experience of a cadaver dissection transforms a medical students' perspective towards life, death and medical profession. In his words, "All of medicine, not just cadaver dissection, trespasses into sacred spheres. Doctors invade the body in every way imaginable. They see people at their most vulnerable, their most scared, their most private. They escort them into the world, and then back out" [49]. Paul feels that, medical students objectify the dead and reduces an individual to mere organs. Paul becomes disheartened when he confronts

the death of his patients. Paul mentions in his memoir about his colleague Dr. Jeff who commits suicide after the accidental death of his patient. The obligation to act for the benefit and interests of patients; beneficence and altruism seem to have a deep impact in the psyche of Dr. Paul and Dr. Jeff. Despite acting in the best interests of their patients, these doctors frequently experience guilt. Dr. Paul tries to view death from the perspective of a doctor and from that of a patient when he becomes a cancer patient [138]. To make sense of death, Paul starts reading illness memoirs of cancer patients. Literature brings him back to life. He tries to come to terms with the reality of his impending death by seeking comfort in writing and reading illness memoirs. Paul exerts all his strength to carry out his duty as a doctor ignoring the physical and emotional struggles related with cancer. Dr. Paul Kalanithi dies two years after the diagnosis of lung cancer. Paul tries very hard to deny his imminent death by seeking comfort in literature.

CONCLUSION

John D. Lantos, M.D. mentions in his book, *Do We Still Need Doctors?* that, the emergence of the bioethics indicates the flaws and limited capacity of the medical profession to create its own system and values for itself. [Lantos, pp 161-162]. Dr. Lantos reviews extensively, the conflicting views held by bioethicists. He also notes that, modern bioethics is dominated by nonphysicians. For Edmund Pellegrino and Leon Kass, the medical profession is a moral enterprise. Veatch and Spicer view it as a technical and scientific enterprise [pp 162-164].

Illness memoirs discussed in the present study address various bioethical principles like beneficence, non-maleficence, autonomy [of the patient] and justice. In *When Breath Becomes Air*, Doctor Paul Kalanithi with his altruistic approach and deeds exhibit medical heroism. He works very hard overlooking his chronic illness. The issues and themes discussed by Dr. Paul Kalanithi in his memoir reflects his idealistic perception about the medical profession. Dr. Gangadharan expresses his concern about the horror inducing metaphor of cancer. He gives importance to the healing aspect of the medical profession and even proposes that chronic diseases can transform the nature of a selfish person. Dr. Vertosick addresses moral conflicts experienced by doctors, patient care and autonomy. Dr. Vertosick and Dr. Atul Gawande states in their memoirs, a few occasions where their diagnosis as well as prognosis went wrong. They acknowledge the challenges and limitations of their profession. Dr. Vertosick also explicitly states how the overly intrusive actions of the medical lawyers complicate the daily duty of a doctor. Other memoirists mentioned in the present study seem to possess a preference for the romanticized and idealized version of the Hippocratic tradition. Focus is given to the inner conflicts of a doctor's mind. Dr. Siddhartha Mukherjee elaborates on the metaphorical seductions of cancer, seems unperturbed about changing

the dreadful image of cancer. He appears to explain away the fear inducing metaphors related with cancer.

The Hippocratic Oath taken by doctors upon graduation from their medical school influences them deeply. The memoirists mentioned in the study seems to live through the moral dilemmas and ethical issues that start with their internship. From their memoirs, readers can comprehend that the Hippocratic Oath is not sufficiently providing solutions for their contemporary concerns and ethical issues. Bioethical principles, the moral questions and ethical concerns encountered by these medical professionals while carrying out their responsibilities seems to leave them at crossroads.

Disclosure statement

No potential conflict of interest was reported by the author[s].

Notes on Contributors

Shamly P* [first author] is a PhD scholar in English literature from the PG & Research Department of English, Farook College, affiliated to the University of Calicut. Her research supervisor is

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Dr. Habeeb C has been working as an assistant professor of English at the Postgraduate and Research Department of English since November 2010. He has completed his graduation, postgraduation, and Ph.D. from Farook College itself. His area of research is disability studies, one of the emerging areas of academic deliberations. He is currently the President of Kerala Federation of the Blind, the largest nonprofit charitable organization of the visually impaired in Kerala and an executive member of All India Confederation of the

blind. His areas of interest include, reading, chess, music, cricket, oratory and training. He has presented papers in various national and international seminars and workshops and has been a trainer in various refresher courses and orientation programs across Kerala. He can be contacted at 9946265483.

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