

The Misdiagnosed and the Undiagnosed: Body and Disease in Gerard Barrett's *Brain on Fire*

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Abstract

The interrelationship between human body, illness and life is a topic of significant discussion in the present times. Medical field has contributed to human existence, increased life expectancy and social security. However, instances in history where bodies are misdiagnosed or undiagnosed, due to lack of awareness, cannot be disregarded. A misdiagnosed illness forces the protagonist Susannah Cahalan in Gerard Barrett's movie *Brain on Fire* (2016) to lead a chaotic life. It continues to make her condition worse, giving a feeling that life will never get better, which gradually results in raising questions related to bodily experiences and pain. The film intends to disseminate medical awareness to ensure autoimmune diagnosis, its treatment, aiming the patient's speedy recovery, since the body is central to human life and existence. This paper attempts to emphasise the need to have a better understanding of the body as well as the current diseases so that it helps in frequent diagnosis and proper medical care, by utilising methods of medical and health humanities.

Keywords: Body; Diseases; Illness; Medical humanities; Misdiagnosed; Undiagnosed.

A medical condition physically exhausts and mentally torments an individual. It results in the loss of track that has been previously directing a person's life. "Illness is the night-side of life, a more onerous citizenship" (3), writes Susan Sontag in her classic work *Illness as Metaphor*. Every one of us, at some point in life, crosses over to this 'other' side for a brief time and some others for longer periods of stay. Chronic illnesses bring about a considerable change to the patient's quality of life and change one's perspective on life itself. Modern medicine as a field of study has come a long way and has also contributed to human existence, increased life expectancy and social security. The advancements in the medical field, owing to the

invention of sophisticated equipments and various discoveries powered by research, should cater to the improved healthcare of human beings. Though disease was initially perceived as a purely-biological incident, our understanding of illness gradually evolved to encompass social, cultural, gendered, economic and psychological aspects. This has led to the evolution and rapid progress of medical humanities, which emerged as a means to use the resources provided by various humanities disciplines, to enhance and critically examine experiences of healthcare and patienthood. Medical humanities deals with the intersection of arts, social sciences and humanities with medical ethics and practice. There has been a lot of discussion about health and diseases with the emergence of medical humanities as a specific genre of inquiry. As a relevant interdisciplinary field of studies, it throws light into the lives, illness, diseases, suffering, diagnosis, healthcare, treatment and other medical experiences of human beings with the importance they deserve. In addition, it provides significant insights and discussions on human experiences/conditions and the trauma emanating from frequent illness and sufferings.

Literature and disease are topics that have not been discussed much until recently. Besides illness and medicine, there is so much to one's medical life, including frequent pain and suffering, anxiety, desolation, the resulting trauma and depression, survival, and so on. "People experience illness within a narrative or story that shapes and gives meaning to what they are feeling, moment to moment" (Donald 17). Contemporary literary texts on medical and health humanities attempt to address patients' subjective experiences using multidimensional perspectives such as 'bioethics'. The rise of narrative medicine, which recognises, narrates and interprets the stories of both doctors and patients about their experiences, is one of the most significant developments in the field of medical humanities. Narrative-based medicine is primarily about listening to, empathising with, and being touched by patient stories, is widely seen as a response to the corporate healthcare industry that commodifies disease and illness. As much as it is important to talk about medical conditions and human health, acknowledging patients' accounts about their illness and giving them a voice also reflect the empathy and compassion of healthcare professionals. Literature and media can highly influence the scientific world of medicine and vice-versa by considering medical perspectives in writings and visual arts. Health humanities therefore unfolds the mysteries of human medical conditions through literally-created works and gives new dimensions to them.

Brain on Fire (2016) is Gerard Barrett's film adaptation of the chronicles

written by the American journalist Susannah Cahalan. The protagonist Susannah Cahalan (played by Chloë Grace Moretz), is a successful young journalist working for The New York Post. She suddenly falls ill, with flu symptoms like cough and fatigue, but later starts showing strange behaviours and sometimes zones out at work and home. The initial physical sufferings give way to temporary mental lapses, forgetfulness, sleeplessness, mood fluctuations, hallucinations, indistinct echoing, noise sensitivity, manic behaviour, paranoia and erratic outbursts later followed by repeated violent seizures. The cause remains unknown and she finds herself hearing and seeing things, such as bedbug bites, leaky taps, and people talking about her. She fails to meet deadlines, and herself owes it to her drinking habits, love life and work stress. Her condition goes from bad to worse. Her doctors also suspect heavy drinking and drug intake and misdiagnose her with bipolar disorder, psychosis and schizophrenia until her family is introduced to an expert in the field of neurology, Dr. Souhel Najjar, who discovers that the right side of Susannah's brain is inflamed, causing her to be fully catatonic. The condition is called Anti-NMDA-Receptor Encephalitis, a rare autoimmune disease which can be treated if properly diagnosed at the right time.

The chances of having an accurate diagnosis and treatment at the right time for recently-discovered or first-time appearing diseases are low. As the body is central to human life and existence, any harm can further become a social problem that needs to be tackled without giving time for the situation to worsen. Treating only the symptoms will not bring any betterment in either the physical or the mental health of the patient. Miss Cahalan struggles to gain medical recognition of her disease. Suffering, even without a name for the disease, is distressing. The fact that doctors are ignorant/unaware of her disease as well as the emotional battering she undergoes cannot be excused, and as a result, the problems double.

“We’ve tested Susannah for every infectious disease that we know of. All of the results are negative.... The tests are saying that she is a healthy young woman... The truth is.... that we don’t know what is wrong with Susannah. We work and make decisions based on facts, and at this point we don’t have any.” (01:04:40-01:06:08)

It becomes challenging for her to deal with what she is going through, without having a complete grasp of the disease. This continues to make her life chaotic until Dr. Najjar, a competent neurologist, discovers her disease and gives it a name. When her diagnosis – central to biomedicine – is taken place and the illness given a name, it helps her calm down her

turbulent mind and go in search of adequate treatment. Moreover, it helps to erase the unnecessary anxieties and doubts of the people around. This calls for the necessity to have a better understanding and awareness about the existing diseases so that it can contribute to timely diagnosis and proper medical care, leading to fast recovery.

Patient-centred care, a medical approach where patients collaborate with their clinical professionals in their journey to cure, is a method in which the individual is placed at the centre of the whole process and his/her words are valued while taking all the critical decisions regarding the treatment. Patient-physician interaction is the primary focus of this approach, and sometimes, relatives also become a part of it if the situation demands. A doctor's overall understanding of the patient's story plays a pivotal role in treating the symptoms as well as the underlying disease. Meaningful interactions between the doctor and the patient not only help in providing appropriate care and treatment but also encourage upcoming medics to listen to their patients closely and to consider what is being communicated so as to offer timely advice. In the movie, the whole story changes when Dr. Najjar enters the scene: "Susannah, I will do my best to help you. I will not hurt you, and I will never lie to you" (01:10:20-01:10:28). The way he keeps encouraging her is positive: "My dear, I know you are in there. I'm going to do everything I can to find you" (01:16:12-01:16:18). He tries to make Susannah walk, draw and touch the parts of her body in order to identify the actual reason for her unidentified illness. Although the patient is fully catatonic, all the further treatment plans are communicated to her without fail, unlike how it was with her previous doctors. In patient-centred care, the patient's concerns and preferences are taken into consideration and a positive relationship between the patient and the doctor is built throughout. Since recovery is aimed at focusing on individual requirements and their active participation, healthcare professionals recognise each patient's mental health as much as their physical health is respected.

Misdiagnosed or undiagnosed cases can upset the peaceful atmosphere of not only the individual but also the person's immediate circle and society at large. Susannah is misdiagnosed multiple times, even by the most prominent doctors in the field. Her father loses his temper at several points: "I don't understand this. My daughter is dying in there... I want answers. It is your job to give us answers... This ain't some kid's club where you get to play doctor. This is my daughter's life. Her life is in your hands and I want answers. Tell me what is wrong with my daughter!" (01:05:23-01:06:00). Her lover, Stephen, is also largely disturbed by her

psychophysical condition: "I know she's still in there. She's just trapped. When I look in her eyes, I can see her screaming to get out. I thought, of all people, you doctors, you know, you'd be able to give us some hope, you know? I mean, that's your job, right?" (01:07:47-01:08:00). This incident points out to the reality that the common man looks up to medical professionals with so much hope, and this pressurises them at large. Even so, it is Susannah's mother who stays stronger than the others, and she reminds the family about the need to push the doctors so that they go with further evaluations. "One is saying bipolar, the next one is saying schizophrenic, then they're saying psychotic.... I think it's just the most convenient explanation for them, so we need to continue putting pressure on them so they continue to investigate" (01:20:00-01:20:40). She keeps on comforting and convincing Susannah's father when he is at his lowest: "If this guy doesn't have the answers, we will go to the next guy or next woman until we find the answer... Because I need you and Susannah needs you" (01:17:30-01:17:55).

Diagnostic procedures are largely time-dependent. Clinical research and surgical pathology give greater importance to time and accuracy. It is the most crucial factor in finding the cause of every condition. The more it gets delayed, the more complicated it becomes. In Susannah's case, it is found that the right hemisphere of her brain is impaired and the next step is to find out the reason for this inflammation. When her parents are in doubt when Dr. Najjar mentions the biopsy of her brain, he reminds them: "Time is of the essence here. I know it sounds invasive, but we are losing her" (01:16:47-01:16:50). Although it becomes successful, the whole process of treatment takes approximately seven months. "Of major importance in the diagnostic process is the element of time. Most diseases evolve over time, and there can be a delay between the onset of disease and the onset of a patient's symptoms; time can also elapse before a patient's symptoms are recognized as a specific diagnosis" (Zwaan and Singh 2015).

The much-discussed discourse of the present times, trauma studies, cannot deny its close association with this grave area of thought and research called medical humanities, as medicine should improve the overall human condition, which encapsulates health and peace. Trauma studies show us the ways through which the survivor of a particular incident comes back to life and make us understand that their fear and suffering are valid. When the brain encounters situations that it cannot process by itself, all of its functioning becomes at risk and reaches a stage where it resists its own capability to handle the happenings around. This eventually becomes a traumatic experience. Survival brain or trauma brain causes one's innate

ability to keep calm to lose, due to which life can turn upside down. It requires constant care and support from an expert team, family as well as friends to get back on track. Though Miss Cahalan feels bad for herself due to a nameless illness with no proper diagnosis or medication indicating the presence of unassimilated trauma, the immense care and support she receives from all corners strengthen her. She apparently cheers herself to articulate those experiences into words so that it helps someone else. It is remarkable how she remembers her past experiences with the rare autoimmune disease and the transformation:

I got used to people asking me about my rare and fascinating illness. I never tried to articulate it, though.... This new Susannah is a lot like the old Susannah, but she's so much stronger. Because for the very first time, I feel ready to tackle the mystery of what happened to me, to find an answer... an answer that could possibly save a life. (01:23:10-01:23:48)

Even in the age of whole-genome sequencing, the medical community can still lack information about many of the common diseases. Undiagnosed or misdiagnosed diseases happen to make the patient lose his/her trust in the doctor and the medicine. As a result, the body gets imprisoned in the frustrated needs of the moment. The movie demonstrates how each disease has its unique symptoms that should be detected separately and meticulously. The majority of tests performed by the healthcare providers should not have been done. However, the Syrian-American neurologist who appears towards the end analyses the case of the young writer from a different perspective, thereby achieving the goal to treat the patient successfully. As a concluding note, the film adds:

“Susannah Catalan was the 217th person to be diagnosed with Anti-NMDA Receptor Encephalitis. Since then, thousands have been diagnosed. Susannah's best selling memoir *Brain on Fire* has helped people all over the world find autoimmune diagnoses and proper treatment.... Susannah continues to raise awareness about these diseases as an author and journalist.” (01:23:49-01:24:15)

Health – physical and emotional – is quintessential for the peaceful existence of human beings on individual and societal levels. Good health and well-being are one among the 17 sustainable development goals put forward by the UN. The misattribution of diagnostic evaluation leads to significant delay in providing effective treatment, hence putting the lives of patients at risk and making them chaotic. *Brain on Fire* becomes a crucial

motivator to increase the level of awareness about different diseases, especially autoimmune diseases that are not easy to diagnose. The film intends to raise medical awareness to find autoimmune diagnoses and treatments which lead to people's speedy recovery since the body deserves better. Thus, it enables the doctors and the frontline workers to think critically and empathically about the issues involved in their practices with the patients.

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