Neurological Disease for Dummies: A Comparative Critique

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If you’re looking for a cheerful feel-good movie to watch with your family, you’re probably better off renting The Shining than either The Diving Bell and the Butterfly or Still Alice. Directed by Richard Glatzer and Wash Westmoreland, Still Alice[s’] Julianne Moore gives a heart-wrenching performance as Dr. Alice Howland, a bright and personable linguistics professor at Columbia University who develops familial Alzheimer’s. In Diving Bell, Mathieu Amalric’s portrayal of a completely paralyzed ex-Elle editor Jean-Dominique Bauby is so gripping that it might as well be Amalric himself reaching into your chest and singlehandedly ripping out your heart. Both movies beautifully illuminate the private struggles that overtake the lives of those involved with disease; however, they seem to glaze over what I would have imagined to be the central focus of any cinema highlighting a serious illness: educating the general public. Though both Diving Bell and Still Alice masterfully portray the physical and emotional struggles dealt with firsthand, through the lack of science these movies succeed in nurturing the fear surrounding neurological diseases, thereby othering the patient and resulting in a quagmire of sympathy and false hope.

I was expecting a movie that depicts Jean-Do’s eye being stitched shut from a first-person viewpoint to be saturated with accurate, medical anecdotes; however, Diving Bell focused more on his thoughts rather than the science of his disease. Disappointingly, Still Alice was no better since it concentrated on those around Alice to such a high degree that it seemed as though the directors almost demoted her to a background character in her own story. The theme of hope versus acceptance is prominent, emphasizing that inappropriate optimism, which is held by everybody besides Jean-Do in Diving Bell, prevents any real progress being made towards acceptance and reframing life. Seeking knowledge on the illness at hand results in witnesses realizing the victim is at the mercy of a merciless disease- and allows victims claiming fault to be liberated from the guilt of “letting” their disease affect their lives.

Realistically, those cliché tag-lines such as, “Think positive!” and, “Stay strong!” do anything but offer comfort or support to the terminal- ly ill; rather, they perpetuate false hope and make a bad situation worse. Henriette, Jean-Do’s speech therapist, refused to acknowledge that no amount of praying would cure him, even going so far as to call him “ob- scene” for wanting death (and then ironically proceeded to walk herself out of his room). There is shame and pressure put onto those with diseases by able-bodied, able-minded spectators, which ultimately can lead the sufferers nowhere but to a feeling of powerlessness over their disease and themselves. (Just what someone who’s dying of an incurable disease needs.) We then see Henriette come back with a changed demeanor; it was almost as if she had lost hope, but this doesn’t lead to demise. Her losing that last shred of optimism for Jean-Do’s recovery allowed her to move past the fantasy of regain and see reality for what it was: terrible but workable. Her magical thinking was inhibiting her abilities to really give Jean-Do what he needed to live fully with his disease, which was demonstrated when she resolved to not aim for full-range mobility and instead change direction and shoot for adaption. Her technique of reciting letters to Bauby, like the T-9 setting on a cell phone, would never have been so successful if she had instead been too busy lamenting over the agonizingly slow progress being made during therapy sessions.

Opposite to Jean-Do’s progress, shown through Jean-Do him- self, Alice’s decline is mainly communicated by those around her, whether it is by her husband who wants to take a job across the country to avoid witnessing her deterioration, her student’s poor class evaluations, or the visi- ble tax her illness causes on her three children. Though disguised slightly better than the medical staff in Diving Bell, Alice’s false hope impedes her abilities to accept and adjust her life in order to accommodate her illness. She first ignores her symptoms and merely tries to consciously get rid of them, subliminally telling the viewers that disease is something within the power realm of the victim, which is false. She then refuses to bring a family member to her neurology appointments, indicating shame about the perceived “weakness.” In another key scene, Alice is seen preparing for her own suicide in such a deliberate, organized, and intellectual manner that it seems like she believes it is possible to avoid her messy death if she planned her decline out academically. This type of behavior ties into the speech therapist’s ("Diving Bell") wishful thinking that there are ways to trick the biological system.

For most of the general population, movies about medical cases have quite the potential to fly above heads, so the scientific aspect must be heavily watered down in order to keep interest levels up. But if a signif- icant amount of medical information is extracted, what will fill the gaps and connect the film? Both Diving Bell and Still Alice sought the answer by resorting to pathos to hook the audience. Sure, Diving Bell labeled Bauby’s ailment as locked-in syndrome and depicted his non-draining eye as a physical complication of the disease, but the movie lacked any suf- ficient medical reasoning, which seemed wasteful. The doctor hardly said anything of medical relevance throughout the movie besides mundane- ly stating that Bauby’s chance of improvement was virtually nonexistent. The amount of neurological information is even less in Still Alice, where the extent of detail basically stopped after labeling the type of Alzheimer’s Alice had, Familial Early Onset Alzheimer’s, and stating that it is genetic and appears earlier than normal- which plenty of people without an MD could have deduced without much effort. This lack of educating information harbors fear of the disease; without factual explanation, there exists a dread that these terrible diseases could strike at any time and no one is safe, which is inaccurate. Humans generally fear the unknown, whether it is people, places, or diseases. This creates a tendency to shy away from those who do have these illnesses. The alienation or “othering” of those with neurological disease is painfully present, proven by the dehumaniz- ing descriptions of these victims. For example, Jean-Do took one look at himself in the mirror and stated that he looked as if he had just come out of formaldehyde (not exactly complimentary). It’s concerning because this in no way helps build empathy and true understanding; rather, the pity that it brings about leads to sympathy, a condescending, superior attitude that doesn’t help to humanize those suffering.

By incorporating more scientific evidence and promoting educa- tion rather than sympathy, the authentic awareness raised could build sincere empathy and support for those affected, thus increasing funding for research and allowing real progress to be made towards cures. Taking the scientific approach could lead to a positive feedback cycle: the more awareness that is received means more money, which then leads to more findings, which then cycles back into leading to more awareness. The pub- lic would no longer throw pity parties for those involved; instead they’d be throwing progress parties.

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