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A Fate Worse Than Death?

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As I drove home on a quiet Sunday night to visit my family, my world suddenly turned upside down. Out of nowhere, a deer emerged and slammed into my car. In an instant, my life was transformed into a nightmare of bright lights, familiar voices, and beeping machines in a cold hospital room. I tried to make sense of what was happening by communicating with my loved ones and the doctors surrounding me, but I was trapped in my own body, unable to speak or move my eyes. I listened as the doctors explained to my parents that I was in a vegetative state, unconscious and unaware of everything around me. But I was aware of everything. Enslaved in my immobile body, I was gripped by fear and panic as people debated whether to end my life. I tried to scream for help, to tell them that I was right there, but no one heard me. It was as if I was locked in an abandoned prison, wandering the empty halls, accompanied by silence and isolation. I began to wonder if this was what it meant to be truly alone, to be trapped in a state of consciousness, unable to communicate with the world around me.

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Section I: Epistemic Injustice Faced by Vegetative Patients

About forty percent of immobile patients thought to be in a vegetative state are misdiagnosed and likely have an experience similar to the one described above (Wade). One in every five people diagnosed as vegetative and presumed to be unconscious are aware of but unable to participate in what is going on around them (Big Think). The vegetative state is often thought of as "wakefulness without awareness" (Owen). Unfortunately, many healthcare providers have failed to use brain imaging to look beyond the initial signs to determine if a lack of movement truly indicates a lack of awareness (Big Think). This apathetic ignorance has led to diagnoses and treatments characterized by injustice. Patient advocates like Dr. Joseph J. Fins have criticized healthcare providers in such cases for premature diagnoses and treatment plans that ignore the need for brain imaging technology to ensure doctors are making informed decisions before withdrawing life support (Chua). The vegetative diagnosis acts as a scarlet letter, branding the patient as not only unresponsive but also unconscious and unaware. The experience of being labeled as vegetative without having undergone appropriate testing can be characterized by what Miranda Fricker calls hermeneutical injustice—a type of epistemic injustice that undermines one's credibility or ability to be considered a knower (Maitra 1). Hermeneutical injustice occurs when a gap in shared resources results in the inability of individuals or groups to understand or articulate their own experiences or when society lacks the ability or resources for an individual to give voice to the injustices they face (Maitra 1). Patients who receive unjust care due to mislabelling experience two types of hermeneutical epistemic injustice: agency-based and semantically-based hermeneutical injustice (Kidd and Carel). In this paper, I argue that a closer examination of these two types of hermeneutical injustice illustrates how alert and aware patients in vegetative states face epistemic injustice. I argue that agency-based hermeneutical injustice poses a greater threat to patients than semantically-based hermeneutical injustice and that it is unethical to exclude appropriate fMRI testing from the diagnostic process.

Section II: fMRI Communication Technology

Dr. Adrian Owen, a neuroscientist and professor at Western University, wrote the book *Into the Grey Zone*, which argues that we can determine levels of awareness and communicate with vegetative patients who are aware using advanced brain imaging techniques. In his book, Dr. Owen explains the diagnostic criteria and tests used by neuroscientists

in vegetative cases. Neuroscientists assess a patient's awareness based on their ability to perform a task known as command following. For example, a patient may be asked to "follow my hand with your eyes." By definition, the vegetative patient is immobile, rendering any command following task inconclusive and ineffective. Therefore, Dr. Owen hypothesizes that if a patient can command follow, as measured by brain activity from imagination tasks, they must be aware but immobile—not vegetative. Instead of asking a patient to move, doctors can present two unique scenarios that respectively represent the answer "yes" or "no." Neuroscientists can use functional magnetic resonance imaging (fMRI) scanners to detect neural activity initiated by the patient's ability to imagine each scenario. The part of the brain that generates thought burns energy in the form of glucose and is replenished through blood flow. Functional MRI is a technique that allows neuroscientists to monitor brain activity through the detection of the blood oxygenation level–dependent signals in the parts of the brain that are activated. This technology can be utilized to detect awareness in and communicate with vegetative patients in the following way: (1) the neuroscientist performs tests to assess the patient's baseline awareness while under an fMRI scanner; (2) the patient is instructed to imagine playing tennis when they wish to answer "yes" to a question, which consistently activates the premotor cortex in a healthy brain; (3) the patient is tasked with imagining walking in their house to answer "no" to a question, which consistently activates the parahippocampal gyrus in a healthy brain; and (4) if the patient could successfully and reliably perform both tasks, a neuroscientist asks the patient questions that elicit a "yes" or "no" response, such as "Are you in pain?" Dr. Owen first found success with a patient named "Kate," who could communicate and respond through this imaginative command following technique despite being misdiagnosed as vegetative. Cases like Kate's, which support Dr. Owen's hypothesis, have profound implications on the understanding and treatment of patients in seemingly vegetative states.

Section III: Agency-Based Hermeneutical Injustice

Agency-based hermeneutical injustice refers to a situation in which an individual's agency or power is diminished in some way, leading to an inability to fully communicate their experiences and needs (Kidd and Carel). In medical situations, this can lead to a lack of understanding or misinterpretation of patient experiences, which often has negative consequences for health and treatment outcomes (Kidd and Carel).

One would think that Dr. Owen's discovery opened many doors for vegetative patients. However, despite the publication of these findings in

2014, healthcare providers ten years later continue to perpetuate agency-based hermeneutical injustice in three main ways (Kidd and Carel).

First, the relationship between voiceless, immobile patients and healthcare providers is characterized by evident power imbalances favoring healthcare providers faced with certain financial realities that can have horrifying implications on diagnostic standards (Kidd and Carel). Few doctors provide fMRI testing for vegetative patients despite multiple professional society endorsements. Limited testing is most likely due to the high cost barrier and unclear guidelines regarding the coverage of fMRIs (Young et al.). Patients face agency-based hermeneutical injustice when their potential agency is valued at less than the $1044 average cost of an fMRI (Ginnetti and Marro). Healthcare providers hold greater power than the patient when deciding whether to include fMRI testing. Although it is the primary responsibility of healthcare providers to prioritize the well-being of their patients, hospitals are businesses, constrained by the limitations of insurance companies. The utilization of brain scans, which could greatly benefit and transform patient lives, is not widely regarded as a part of the diagnostic standard by doctors or insurance companies, leading to agency-based hermeneutical injustice (Young et al.). The lack of clear and uniform fMRI coverage by insurance companies is unethical considering Dr. Owen's findings. Healthcare providers similarly face ethical concerns when failing to acknowledge the crucial role fMRI testing plays in detecting consciousness in patients with brain injuries to not only inform care but radically alter treatment trajectories and patient lives (Young et al.). Patients are victims of agency-based hermeneutical injustice in any instance in which their doctors—tasked with acting as fiduciaries—exclude endorsed and validated fMRI assessment in their testing, especially when this choice is made for monetary reasons.

Second, healthcare providers distribute unequal (less adequate and considerate) care and support for patients unable to express themselves than for patients with more agency (Gopinath et al.). Aware but immobile patients' pain and experiences remain invisible to their doctors and families as they are unable to express their needs without the help of the neuroimaging they are denied. The audience effect in social psychology highlights the questionable ways in which some act and behave when we think that others will not or cannot report our behavior. Cases like Nathan Sutherland—a nurse who sexually abused a vegetative patient in his care who later gave birth to his child—highlight the vulnerability of vegetative patients to neglect and abuse (Paz). Vegetative patients face agency-based hermeneutical injustice when being denied access to their only ability to demonstrate awareness and communicate their less-than-adequate or, in some particularly tragic cases, dangerous experiences.

Third, doctors may recommend a life-ending health plan for vegetative patients without any consultation or testing to confirm the patient's level of awareness, leaving the patient without a say in decisions about, in some cases, hastily ending their life (Kidd and Carel). The agency-based hermeneutical injustice faced by patients who are aware, unbeknownst to their doctors, has tremendous implications for their treatment plans. Family members tasked with making medical decisions on behalf of the vegetative patient may also face epistemic injustice in cases where they are denied relevant data points such as the availability of fMRI testing and research like Dr. Owen's. The absence of this information could result in healthcare decisions without a complete understanding of the patient's condition. A healthcare decision for a vegetative patient made without a complete understanding of their condition, such that it lacks fMRI testing, is a decision based on a level of awareness that is inadequate and unethical.

Agency-based hermeneutical injustice highlights the need for better testing and communication between patients and their medical professionals, family members, and insurance companies to ensure that the best possible care is provided for patients misdiagnosed as vegetative.

Section IV: Semantically-Based Hermeneutical Injustice

Semantically-based hermeneutical injustice involves a patient's lack of access to appropriate vocabulary or concepts to articulate their experiences and needs to healthcare providers and society (Kidd and Carel). Immobile but conscious patients are subject to semantically-based hermeneutical injustice when they lack access to articulate more complex experiences or needs. Command following is constrained by yes or no answers. If patients are given the opportunity to communicate at all, they are limited to communication techniques that may hinder their ability to express complex thoughts or emotions. Neurologists utilizing fMRI technology may fail to ask patients about certain thoughts or desires they wish to express. Agency-based hermeneutical injustice aside (when the patient's awareness is not assessed or discovered, the families are not informed about relevant fMRI testing, and doctors exclude relevant fMRI testing for whatever reason), unspoken and unasked questions remain beyond the patient's reach. Vegetative patients who are also victims of abuse and neglect, as in the Nathan Sutherland case, may be asked about their pain level, but not about their safety. Without access to appropriate communication tools and accommodations, these patients face semantically-based hermeneutical injustice, as their experiences and needs are not fully recognized or understood by others due to limitations in language and shared understanding (Kidd and Carel).

Although semantically-based hermeneutical injustice is a considerable threat, at present, agency-based hermeneutical injustice poses the gravest danger for vegetative patients as their considered agency and treatment trajectories change in far more significant ways when consciousness is discovered. Failing to provide fMRI testing disregards a basic ethical obligation to use resources available to rule out life-altering diagnoses and to diagnose accurately. In restricting access to available diagnostic and communicative technology, responsible healthcare providers engage in patient neglect by violating their role as a fiduciary. While current technologies face constraints that can lead to semantically-based hermeneutical injustice, even limited tools allow for transformative progress in understanding patient needs and altering patient lives. Regardless of which hermeneutical injustice is most threatening, research and funding should be allocated to improving the ways in which we communicate with those under our care such that they are not subject to semantically-based hermeneutical injustice.

Section V: Objection

Although it seems clear that these patients are experiencing profound suffering, one could argue that their situation is not best defined as epistemic injustice. Instead, patients labeled as vegetative who are aware are facing a different kind of humanitarian injustice. This argument would primarily center around the constraints regarding the accessibility of resources and technologies needed for a comprehensive evaluation of a patient's cognitive abilities and effective communication with them. Similar to how certain individuals in the United States healthcare system are denied treatments or faced with crushing debt for treatments made on their behalf while unconscious, such as scans and emergency surgeries, vegetative patients face a similar financial injustice. The healthcare industry, like most others, has finite resources, and this problem may best be characterized by questionable ethics when faced with financial realities rather than as epistemic injustice.

Although financial constraints can certainly be a preventative feature for best and most ethical healthcare practices, this constraint does not negate but rather underscores the epistemic injustice in vegetative-but-conscious cases. It is precisely because of the epistemic injustice in such cases that financial constraints become a problem. While we cannot expect medical professionals to run every test in the book, it would be unethical to suggest that healthcare professionals, acting as fiduciaries when making diagnostic or treatment decisions at any point in a patient's journey, do not conduct thorough and relevant testing for their patients. As a validated and

endorsed testing procedure by respected professional medical societies, financial burdens should not be the barrier to adequate care (in this case referring to the inclusion of fMRI scans in the diagnosis of a vegetative patient). While the ethics of financial concerns in healthcare practices is an important consideration, it does not undermine the fact that vegetative-but-conscious patients face epistemic injustice.

Section VI: Conclusion

Communication is a crucial aspect of human well-being (Umberson and Montez). Through fMRI technology, it is now possible to return the ability to communicate to some patients who may have thought they lost their agency forever. Despite the conclusive results, most patients diagnosed as vegetative are not given the opportunity to communicate through fMRI scans. The lack of fMRI access deprives patients of ethical care and the ability to advocate for themselves. The omission of Dr. Owen's findings keeps family members in the dark in unethical ways, particularly when family members are responsible for making treatment decisions on behalf of the patient. Agency-based hermeneutical injustice faced by patients highlights the need for healthcare providers to recognize and support the possible agency and autonomy of people in vegetative states and to work towards creating more inclusive and supportive environments that allow for their full participation and integration in medical decisions. Semantically-based hermeneutical injustice faced by patients underscores the importance of continued refinement in communication technologies. Considering this, healthcare providers and families alike must be made aware of the potential for misdiagnosis and the availability of new technologies that can change patients' lives so that they, too, are not subject to epistemic injustice. By doing so, we can ensure that patients in a vegetative state do not endure unjust or harmful treatment and can express their needs, feelings, and thoughts if possible. Shockingly, this topic has received minimal attention in academic literature. The information in this paper just begins to scratch the surface of the injustices faced by vegetative patients. It is time to recognize the humanity and potential agency of patients in a vegetative state by bringing more attention to this topic and by providing patients with the resources and support they need to live fulfilling lives.

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