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Neurological Reflections on Social Stigma

SERGIO LANATA

One of the most common diseases of the brain, epilepsy affects roughly 50 million people worldwide. The disease features sudden and often violent convulsions, or seizures, which for most of epilepsy’s recorded history were interpreted as a form of divine punishment. Hence epilepsy was known as The Sacred Disease in ancient medical texts and was treated by priests, not physicians. One of the earliest recorded attempts to rectify this narrative of the disease appears in The Hippocratic Corpus, a collection of medical texts linked to the work of Hippocrates and written more than two-thousand years ago.

In one of these texts, titled On the Sacred Disease, the author provides lucid, empirically based arguments to support the idea of epilepsy as a form of brain disease, and boldly concluded that “men regard [epilepsy’s] nature and cause as divine from ignorance and wonder.” Still, brain-centered views of epilepsy remained hypothetical during the life of Hippocrates and for centuries after his death, while supernatural narratives of epilepsy prevailed. Consequently, for countless generations since the ancient Greeks, people living with epilepsy throughout the world were commonly seen as sinful or immoral, even deserving of their condition, and were mistreated in the most atrocious ways imaginable. This history and its painful human toll has been painstakingly captured by Owsei Temkin in The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology.

Today, epilepsy is considered a treatable, often curable brain disease. Yet millions of affected people, especially those living in low- and middle-income countries, still endure various forms of social injustice and abuse, too often eerily reminiscent of the treatment people with epilepsy faced hundreds of years ago. In many regions of Saudi Arabia, for example, people with epilepsy are commonly thought to be possessed by Jinns, the Arabic term for demons or devils. As in the time of Hippocrates, they are marginalized, mistreated, and subjected to potentially harmful “curative”
interventions such as cautery. In sub-Saharan Africa, supernatural narratives of illness for epilepsy are very common, ranging from witchcraft to demonic possession, and leading to equally distressing and dehumanizing interventions.

This social challenge has not been systematically studied throughout the world, but similar supernatural narratives exist in many countries, including in Egypt, Laos, Pakistan, Peru, and Iran. Although most research suggests that supernatural narratives of epilepsy prevail largely in socioeconomically vulnerable regions, these narratives have also not faded from affluent, well-educated European and North American societies. Today epilepsy remains one of the most socially stigmatized human conditions worldwide.

Social stigma is operationalized differently across different fields of study. Yet at their core, all operational definitions of social stigma describe a series of interdependent steps, a cascade of events, beginning with cognitive-emotional processes and ending with harmful attitudes and behaviors against those being stigmatized. First, to stigmatize is to cognitively “mark” a person, or group of people, as different from others based on socially identifiable characteristics. Then, there’s the emergence of negative stereotypic beliefs about the stigmatized individual and group; these beliefs are eventually shared among dominant groups, thus creating a collective sense of “us” vs. “them,” a sense of othering. Lastly, these stereotypical beliefs become factual to dominant groups, thereby fueling and justifying acts of exclusion, avoidance, aggression, or other forms of mistreatment committed against those being stigmatized.

The social stigma that surrounds the lives of people with epilepsy also threatens the lives of millions others living with other forms of brain disease, including psychiatric disease. Studies show that, as a whole, people with chronic disease of the brain experience more stigma than those with non-neurological disease. People living with serious psychiatric disease in vulnerable regions of West Africa, for example, are commonly treated as if possessed by demons, are involuntarily chained to trees in so-called “prayer camps” lead by religious priests and pastors, and are subjected to harmful supposedly curative interventions. In my own practice as an academic neurologist and neuropsychiatrist in San Francisco, I’ve had to confront beliefs of sorcery firmly held by a family coping with an autosomal-dominant genetic form of Alzheimer’s disease, a narrative that for generations had led to various forms of injustice and mistreatment against family members affected by the disease.

Why are societies around the world so prone to stigmatizing people living with brain disease? I believe the answer to this question is simple and
unsettling. Chronic diseases of the brain rob us of core human traits - our sense of self - in ways that are often obviously visible to others. People with brain disease are therefore easily “marked” by society, thereby igniting the social stigma cascade described above. Indeed, different brain diseases can lead to changes in movement, coordination, memory, language function, emotional expressivity, critical thinking, mood, personality, and practically every other trait that shapes the human experience.

In addition, unlike the lived experience of most people with non-neurological diseases, those with brain diseases experience little to no space between “I” and “my illness,” further adding to the visible social vulnerability of those affected. With brain disease, it isn’t “my breathing,” or “my chest,” or “my kidney,” or “my toe” that is ill, it is the “I” who is ill. This attack on a person’s core sense of self and the ensuing social vulnerability lead people living with brain disease to become easily “marked” by society, thus initiating the stigma cascade.

How can we address this tremendous social challenge and its associated human pain and suffering? Every neurologist caring for a person with brain disease who is being stigmatized at work or at home, or holds self-stigmatizing beliefs about their own brain disease, knows the power of education in stopping the cascade of social stigma. When I counseled the family who spoke of sorcery and witchcraft as the cause of the autosomal dominant genetic form of Alzheimer’s disease that had affected several family members, I didn’t attack their beliefs. Instead, over several meetings, I methodically inserted knowledge of the disease using historical perspectives, current medical knowledge, as well as my own personal experience treating other patients with similar disease. I brought in a geneticist into the conversation, and together we presented knowledge so clearly and convincingly that ideas of sorcery inevitably lost their grip in the minds of some family members; suddenly, espousing to these beliefs became unnecessary, irrelevant. Based on my experience, the effective diffusion of knowledge of the brain-basis of these diseases allows families and individuals to see past their belief-driven fears and enables them to act from a place of understanding, which promotes empathy and compassion for those affected.

Perhaps following the lead of clinicians, practically all published interventions and programs aimed at mitigating social stigma around brain disease are grounded on education about the different forms of brain disease. Simply educating people about specific brain diseases doesn’t go far enough, however. We must address the most upstream components of the social stigma cascade by asking ourselves an important question: Why are societies so prone to come up with - and accept as true – supernatural
narratives of brain disease to begin with? The author of *On The Sacred Disease* offered a succinct response to this question that remains relevant today: Ignorance and wonder.

Ignorance fuels these beliefs. The fact that millennia ago entire societies held harmful supernatural narratives of illness for epilepsy and other brain diseases is understandable, perhaps even expected considering that supernatural views of the natural world were widespread at the time, while scientific thought was in its infancy. Yet since so many societies still hold similar narratives of illness, we should be alarmed about how inadequately our knowledge of the human brain – not merely awareness of individual brain diseases - has seeped into the collective consciousness of societies around the world. This gap in knowledge creates a cognitive void that is naturally and readily filled with unsubstantiated supernatural beliefs.

The author of *On The Sacred Disease*, more than two-thousand years ago, had already perceived the urgent need to educate society about the brain’s central role in enabling the entirety of the human experience, perhaps precisely as a way of preventing the emergence and spread of harmful narratives of brain disease that lead to social stigma:

Men ought to know that from nothing else but the brain come joys, delights laughter and sports, and sorrows, grieves, despondency, and lamentations. And by this, in an especial manner, we acquire wisdom and knowledge, and see and hear, and know what are foul and what are fair, what are bad and what are good, what are sweet, and what unsavory... And by the same organ we become mad and delirious, and fears and terrors assail us... All these things we endure from the brain... In these ways I am of the opinion that the brain exercises the greatest power in the man.

Most people reading this passage today, however, would experience the same degree of ambivalence the ancient Greeks must’ve felt about the idea of the brain playing such a central role in their lives. Yet everything in this passage has been validated through careful empirical observation. As a neurology trainee, I vividly remember meeting families who could fathom that their loved one’s stroke had caused weakness, but struggled, at an almost existential level, to comprehend that the same stroke had caused their loved one’s inability to be aware of their own weakness (anosognosia), or their inability to speak (aphasia). These changes, families often felt, were due to something else - perhaps they were intentionally denying their illness as a way of coping with it, or perhaps the emotional trauma of the stroke had made them mute.
Currently, as a neurologist specialized in dementia, I continue to see similar gaps in knowledge and similar narratives of illness while evaluating, treating, and counseling individuals and families struggling with different forms of neurodegenerative disease. Across all socioeconomic and sociodemographic groups, people struggle with the notion that a very physical disease process of the brain leads to changes in emotional expressivity, behavior, and personality, for example. In my practice, I am frequently reminded that most people see the brain as dictating only the most elemental of human functions, leaving the more complex and subjective experiences to something else entirely, not at all dependent on the brain.

Wonder also fuels supernatural beliefs about brain disease. Of all the ways a person may respond to witnessing, or being affected by, a seizure for the first time, wonder is probably the most universal response. Even in cases when the initial response is fear or panic, wonder would probably be a quick second. It’s the experience of wonder that stirs in us the urge to understand why and how a mysterious event occurred. History suggests that when the experience of wonder about the signs and symptoms of brain disease occurs in the setting of widespread societal ignorance of the brain, we tend to make sense of these manifestations using religious, spiritual, mystical, or other supernatural beliefs. Wonder invites belief, too often in damaging or harmful ways.

To my knowledge, no research systematically investigates the influence of specific supernatural belief systems on societal conceptions of health and disease, particularly brain disease. Some research does suggest, however, that a substantial proportion of people, across various socioeconomic and sociodemographic backgrounds, believe that external forces, beyond their reach, control their health. Psychologists developed the concept of locus of control to describe the degree to which a person believes that a specific situation or life event is under their control, as opposed to it being under the control of external, unreachable forces. When applied to health, research suggests that people who believe in an external health locus of control (HLOC), versus an internal one, are generally less motivated to seek knowledge that would enable them to take care of their personal health, thus resulting in more frequent emergency department visits, for example.

Within the field of brain disease, the bulk of HLOC research has focused on mood disorders. In a sample of older adults from Iran, for example, researchers found that subjects who adhered to an external HLOC paradigm had higher rates of depressive symptoms compared to those who scored higher on internal HLOC measures. Similar findings were reported in a study of
depression and HLOC conducted on a sample of university students in Botswana. And in a study conducted in the United Kingdom, adherence to an external HLOC was found to mediate up to a third of the estimated association between early life socioeconomic adversity and teenage depression. In sum, the majority of studies investigating associations between HLOC and different forms psychiatric disease show that strong adherence to an external HLOC paradigm is associated with worse outcomes compared to adherence to an internal HLOC.

It’s hardly surprising that a noteworthy proportion of people with brain disease adhere to external health loci of control, and that supernatural narratives of illness still prevail throughout the world today, when one considers that that approximately 63% of the world’s adults believe in God with “absolute certainty,” and 53% of adults believe religion is “very important” in their lives, according to the Pew Research Center. This doesn’t suggest that believing in God or adhering to any religious doctrine is intrinsically wrong or problematic. To the contrary, the concepts of God and religion serve an important role in addressing many of the life’s enduring mysteries and uncertainties.

In 2019, however, godly or religious narratives should not be used to fill the vacuum created by individual and societal ignorance of the human brain in health and disease. I’m not proposing an affront on God and religion, but rather an ambitious effort to introduce knowledge of the brain into the collective consciousness of societies around the world, and with that knowledge letting people decide on the limits of God and religion.

In our day and age, when the reach and influence of the internet and social media appear limitless, the societal impact of both brain-based education and pseudoscientific misinformation cannot be overstated. Given the reach and influence of misinformation that currently proliferates through modern media streams, an increasing number of scholars believe the world is now experiencing a scientific knowledge crisis with potentially deadly consequences. This is especially so within the fields of neurology and neuroscience, given that, as discussed in this essay, long before the advent of the internet and social media, societies have demonstrated a troublesome tendency to adopt harmful, unsubstantiated supernatural beliefs to explain natural brain phenomena.

On the other hand, the history of neurology also teaches us the powerful role that social activism, rooted on brain science, can have in ridding societies of these harmful narratives of illness. Ultimately, it is for this reason that the social stigma surrounding the lives of people with brain disease in affluent societies today is significantly less prevalent than that of socioeconomically vulnerable societies. As creators, keepers, and
curators of our knowledge of the brain, neuroscientists and neurologists are uniquely positioned to exert social change in this regard.

First, we (neurologists and neuroscientists) must see ourselves as more than tightly circumscribed professionals. We are potentially powerful vehicles of social change. Second, to best leverage the reach and influence of modern media streams, we must seek highly innovative partnerships with non-scientists, especially artists, in order to transmit this knowledge via artistic mediums that have a proven track record of changing the collective consciousness of societies all over.

At our center, the Memory and Aging Center at University of California, San Francisco, many of my colleagues and I view ourselves as vehicles of social change. I direct our center’s community outreach program, which holds brain education as one of its core aims. We educate vulnerable communities in the San Francisco Bay Area on various topics pertaining to the brain and brain health. Our outreach program is generously supported by the Global Brain Health Institute (GBHI), an innovative collaboration between Trinity College in Dublin, Ireland, and the University of California, San Francisco. The GBHI is one of six international programs in Africa, Europe, Asia and Australia that address health, economic, and racial inequities to advance fairer, healthier, more inclusive societies worldwide.

Within the GBHI, we house the Atlantic Fellows for Equity in Brain Health training program. We train 30 to 40 international and interprofessional leaders annually on various aspects of brain health and dementia prevention strategies, with an emphasis on vulnerable populations. Uniquely, many of our trainees are artists who, working collaboratively with neurologist and neuroscientists, have led the creation of socially impactful projects. These artists learn about the brain in health and disease through traditional lectures and readings, but perhaps more importantly, they spend valuable time with neurologists and neuroscientists, shadowing them in the clinic and in the lab, where they can observe the manifestations of brain disease at every stage of illness.

We’ve trained an accomplished photojournalist from Peru, for example, who learned about the impact of various social determinants of health on brain health and dementia risk. He has launched an ambitious project to document, through photography and narrative, the impact of various social and environmental forces on the aging trajectories of older Peruvians with the goal of bringing social awareness of brain health challenges in Peru. We also trained a Bay Area comedic monologist who, after spending a year with us, began a project called “Citizen Brain,” a video series that connect brain science with social justice by examining empathy and stigma through the unique lens of art and neuroscience. By giving artists the
opportunity to learn neurology and neuroscience through hands-on, experiential educational opportunities, they naturally find ways to use their artistic mediums to spread knowledge of the brain in accessible and powerful ways.

The history of epilepsy is also that of numerous other diseases of the brain, especially the psychiatric and neurodegenerative diseases. It is the collective story of people who, as a result of brain disease, experience often striking changes in the very essence of what makes them human; changes that in a social background of ignorance of the brain’s role in enabling every aspect of the human experience, too often lead them to endure social abuse and injustice fueled by supernatural narratives of illness. In short, ignorance leads to fear, fear leads to belief, belief leads to suffering.

On the other hand, the history of epilepsy and other brain diseases also stands as a powerful testimony to the transformational role that social activism, rooted on brain science education, can have in rectifying harmful narratives of illness. Neurologists and neuroscientists must see themselves as powerful agents of social change and seek creative and innovative ways of introducing knowledge of the brain into society with the hope of reducing social injustice. No effort is too small or too large in this regard, and partnerships with non-scientists, especially artists, are crucially important for the diffusion and acceptability of this important knowledge.

More broadly, the effective and innovative transmission of basic knowledge of the human brain into the collective consciousness of societies around the world holds great potential for contributing toward the mitigation of other forms of social stigma and injustice that are similarly enabled and fueled by divisive social narratives that have no basis in biology. The fields of neurology and neuroscience robustly substantiate the idea of human equality, as well as the idea of human individuality. That is, at the level of the brain, all human beings, regardless of race, ethnicity, cultural background, or any other socially-defined categorization, share a common neuroanatomical blueprint that dictates our universal human experience. Although relatively minor neuroanatomical variations exist within this blueprint at a physiologic and histological among all individuals, variations that contribute to each person’s individual character and personality, for example, are not exclusively contained within any socially-defined group. More bluntly, skin color is not a reliable proxy of neuroanatomical difference.

No effort is too large or too small when it comes to the importance of educating societies, especially socioeconomically vulnerable ones, about the human brain in both health and disease. But to the extent possible, neurologists and neuroscientists must seek ambitious collaborations
with non-scientists to effectively diffuse this knowledge into the collective consciousness of the world, with the hope of mitigating various forms of social injustice.

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RECOMMENDED READINGS


Mecarelli, Oriano, Giuseppe Capovilla, Antonino Romeo, Guido Rubboli, Paolo Tinuper, and Ettore Beghi. 2010. “Past and Present Public Knowledge and Attitudes toward Epilepsy in Italy.” *Epilepsy & Behavior* 18 (100).


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