
Vox Clamantis

What Biology Can't Do

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I was relieved to learn I had a brain disorder. I made the discovery by accident when, in 2000, a local radio show asked a well-known headache specialist to speak on migraine. He started with a familiar if frustrating narrative. “We used to believe that migraine was a disorder of neurotic women, whose blood vessels dilated and they couldn’t face up to life.” But I jumped out of my seat when he continued, “We now know that migraine is a disorder of the brain.” Was this medical expert finally confirming that migraine was a “real” disorder? However, the first listener calling into the show deflated my spirits. He had migraine and now he worried that this indicated something seriously wrong with his brain. His sensible anxiety highlighted the irony of my position. How did I arrive at a point where I delighted in the diagnosis of a neurobiological disease? And, more importantly, why was I so certain that having an identified biological problem would make my pain and suffering real to other people?

Certainly, validation had been a long time coming. When I was age five, a pediatrician diagnosed my recurring headaches as a symptom of a “Type A personality.” When I was 18, a psychologist suggested that my migraines were brought on by the

stress of not having a boyfriend. Just a few years before the radio broadcast, an allergist had prescribed yoga for my pain. “You just need to breathe.” Yoga may be generally beneficial to health, but the suggestion felt dismissive when given without so much as a diagnosis. Was I just a hypochondriac? Nobody could explain why something as banal as a “headache” kept me in bed all day. So, while I lived with chronic pain, in retrospect, it was this pervasive sense of shame that created my most acute suffering.

Migraine affects between 10–12% of the world’s adult population, three-quarters of whom are women.¹ A nontrivial *additional* portion of the population (between 1 and 4% of adults, worldwide) have chronic migraine and experience headache days more often than they don’t.² People with migraine often miss work, underperform at their jobs, struggle to care for their families, and neglect social obligations.³ The social and economic consequences of migraine are so overwhelming that the WHO’s 2010 Global Burden of Disease survey estimated that migraine is the 8th leading cause of disability worldwide.⁴

And yet migraine patients consistently report that everyone – from doctors and employers to friends and family – has trouble accepting that something that seems like a common nuisance,

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rather than a serious disease, can wreak so much havoc in their lives.⁵ Migraine leaves few marks, so no objective test can “prove” that someone has a migraine or assess the intensity of the pain, all of which easily leads to suspicions that a person who regularly complains of migraine must be malingering. As a result, people who are disabled by their migraines feel extraordinary levels of stigma, which is exacerbated by shame and a sense of moral weakness when they cannot fulfill their duties.⁶ As Joan Didion wrote: “All of us who have migraine suffer not only from the attacks themselves but from this common conviction that we are perversely refusing to cure ourselves by taking a couple of aspirin, that we are making ourselves sick, that we ‘bring it on ourselves.’”⁷

The “common conviction” to which Didion refers has a history. Migraine has long been treated as a trivial disorder of privilege or a clumsy excuse – a sentiment perhaps best captured in the cliché “not tonight, dear, I have a headache.” Eighteenth-century poet Alexander Pope portrayed Belinda, protagonist in *The Rape of the Lock*, as pensive in bed with a “megrim,” as she mourned the loss of her favorite curl of hair. Beth, the weakest and most sensitive of Louisa May Alcott’s *Little Women*, is also the one who has headaches. When Virginia Woolf’s Mrs. Dalloway suffers a migraine that forces her to bed even as she must prepare for a party, we are to read it as a sign of both her privilege (her housekeeper continues the preparations) and her sexual repression. More recently, Ian McEwan represented the distant, repressed, and morally culpable mother in *Atonement* as having severe migraine.

Stereotypes of migraine as a disorder of the neurotic and privileged are also threaded throughout the history of migraine medicine, despite the fact that biological explanations of migraine have existed for a long time. For example, although many Victorian doctors thought of migraine as a vascular problem, they portrayed the migraine patient as someone with a nervous disposition. John Symonds (1807–1881) described such people as “persons of very lively emotions and delicate sensitivity, easily perturbed mind, easily put off their sleep, [and] those who have the aesthetical

and imaginative elements highly developed.”⁸ The influential English doctor, PW Latham (1832–1923), agreed, writing that people with migraine possess “brains [that] are very excitable, their senses acute, and their imaginations free.”⁹

Twentieth century neurologist Harold G. Wolff (1898–1962) became famous for his experiments demonstrating that migraine pain involved the dilation of the vascular system and, therefore, was physiological. But Wolff, who had studied under some of the greatest thinkers in psychobiology, including Stanley Cobb, Otto Loewi, Ivan Pavlov, and Adolf Meyer, was interested in understanding how individual psychology contributed to migraine. Ultimately, he located the *cause* of migraine in the psyche and, more specifically, in the personality. Emotions, to Wolff, were legitimate targets of medical intervention, writing: “Loves Hates Fears are as real as management of lump [*sic*] in the chest or pus in the pericardium.”¹⁰ His highly influential “migraine personality” thesis described patients as ambitious, successful, competitive, and efficient. This somewhat flattering description was based not only on his wealthy Upper East Side clientele at Cornell Medical School, but also on his own migraines and obsessive work ethic. Yet, when Wolff described women with migraine, the terms of his explanation were revealingly different. Their obsessiveness pertained not to work, but to needless worrying about small annoyances and a pathological resistance to feminine duties, especially sex. Women with migraine, he wrote, only had sex as a marital duty. They certainly didn’t enjoy it.

Wolff’s contemporaries were comparatively less interested in the biology of migraine and focused on the psychological problems facing women with migraine. Walter Alvarez (1884–1978), a mid-century leader in headache medicine, dismissed women patients, stating in a 1963 article that “It is an axiom with me that whenever a woman is having three attacks of migraine a week, it means that she is either psychopathic or else she is overworking or worrying or fretting, or otherwise using her brain wrongly.”¹¹ By the late 1960s, physicians in the journal *Headache* generally agreed that women with migraine were psychopathic. “Migraines,”

wrote one psychologist, “permit hostility and irritability displays within the limits permitted by the excuse ‘I have a headache.’”¹²

Against this history, it makes sense that people with migraine so often wish “bad” news upon themselves. If a tumor could make a doctor like Alvarez take us seriously, then bring it on. But this desire produces an incongruous effect. For example, advocates celebrate research that correlates migraine with fatal diseases like stroke or visible brain lesions – clearly undesirable conditions – not only as a major advance but also as a public relations victory that might attract research, policy, and public attention. Positioning migraine as a neurobiological disorder seems not only like the most promising way to develop treatments for migraine but also a way to transform how we understand the migraine patient.

However, this strategy has only produced mixed results for advocates of other diseases. For example, for 25 years, mental health advocates have run public health campaigns that have tried to reduce the stigma of depression and schizophrenia by advertising that these diagnoses are biological and, therefore, diseases “like any other.”¹³ Studies have now shown that while the public is now much more likely to support treatment for mental illness, brain-based explanations of depression and schizophrenia appear to have had little effect on stigma. People still fear and exclude the mentally ill.

The reason why biology is not sufficient to overcome stigma remains unclear; however, the caller to the radio show points out at least one problem: there is a central tension built within the framing of migraine as a neurobiological disease. In an attempt to convince the public that migraine is a legitimate disorder, headache specialists have portrayed people with migraine as having “different” and potentially “damaged” brains. While this strategy might convince people that migraine sufferers are not responsible for their ailment, possession of a damaged brain might do little to alleviate the stigma associated with migraine.

The second problem is that biology cannot transcend culture. In fact, rather than replace the cultural mythologies that surround migraine, contemporary medical representations of the

“migraine brain” might reinforce these stereotypes. The new neurobiological framework for migraine generally presents the person with migraine as someone who has inherited or developed a hyperexcitable or sensitive brain. This brain is represented as one that requires stability and abhors stress, and which demands a calm, stable environment. One contemporary self-help book describes the migraine brain as “high maintenance.” Some neurologists have even argued that, like the 19th century nervous temperament, the migraine brain’s enhanced responsiveness produces advantages like empathy and intuition. Given historical context, these descriptions read like neurobiological versions of the same tropes that have plagued migraine patients for centuries. The “migraine brain” is not much different than Latham’s nervous temperament. The excitable, neurotic migraine personality has morphed into patients with excitable, neurotic brains. The locus of responsibility may have changed, but the moral character associated with the typically female patient who gets migraine is still scrutinized.

Pharmaceutical advertisements designed to sell new drugs only magnify these cultural stereotypes. These ads, which in the US are marketed directly to consumers, usually represent migraine as a disorder experienced by well-off, white women, whose migraines are a response to the everyday stresses of jobs and childcare. Take, for example, an advertisement that Allergan ran for many years. A slender, attractive woman lies on a sofa in a park, while children play in the background (Fig. 1). The slogan “you’re living a maybe life,” refers to her inability to engage with her family. The advertisement works because it exploits a highly gendered form of guilt. It also reinforces multiple longstanding representations of migraine: that it is a disorder of those who can afford to take time off; that it happens to those who cannot handle their everyday lives; and that it is primarily a disorder of a certain kind of woman. Their new campaign, which shows a woman who is not in pain engaging in a number of leisurely activities like biking along the beach, is hardly better. Aside from perpetuating the myth that migraine is a middle-class, women’s disorder (migraine is actually more prevalent in lower socioeconomic-status populations and

When you have migraines with 15 or more headache days a month, maybe you can really be there, maybe you can't.

Well, Maybe it's time you changed that.

Start today by finding out if you have Chronic Migraine. Knowing that what you've been living with has a name, means knowing you can find treatments that are right for you. After all, saying "yes, I'll be there"...and really being there...shouldn't be a luxury.

Fig. 1.—Allergan advertisement featuring woman prostrate with migraine.

one-third of people with migraine are men), these ads also serve to reinforce the stereotype of migraine as an excuse.⁵

These unfortunate stereotypes persist for many reasons. The pharmaceutical industry is in the business of selling drugs, not running public health campaigns. Their ads seek to construct and represent their target audience, rather than reach underserved populations or boost the status of migraine. As such, the pharmaceutical industry does a remarkably good job of representing a particular subset of clinical patient populations that doctors are accustomed to seeing. Patients who manage to overcome whatever barriers keep half of those with migraine from seeking medical help very often are whiter, wealthier, and more female than the general

population of those with migraine. But it would be a mistake to forget that migraine is a big public health problem that affects groups that most clinical patient populations and the cultural mythology of migraine render invisible: men, people without insurance, people living in poverty, and people of color, to name just a few.

The stubborn belief that migraine patients are more neurotic, excitable, or stressed than others poses additional challenges. Epidemiological evidence suggests that migraine travels with affective disorders like depression and anxiety.¹⁴ But again, this phenomenon is magnified for doctors, as clinical populations not only tend to have the most difficult migraines to treat, their patients have the most psychiatric comorbidities. These comorbidities

certainly create difficulties in clinical practice, not least of which is caring for patients who may have had multiple negative experiences with previous doctors who failed to understand or believe the severity of their symptoms. Doctors also must take care not to conflate the challenges of treating particular patients with characteristics of an entire disease population. At the same time, headache specialists concerned with legitimating and destigmatizing migraine should not shy away from studying migraine's very real psychobiological associations, many of which disproportionately affect those with fewer resources. Western culture may privilege biology over psychology (or sociology for that matter), but doctors ought not fall into that trap. Instead, the focus should be on finding ways of researching and representing the entire spectrum of migraine in ways that don't rely on the same old gendered tropes and metaphors.

The danger of allowing gendered stereotypes to persist has widespread implications. Not only do these representations stigmatize people with migraine by creating assumptions about their moral character, they also have a negative effect on care for patients of both genders. Women with migraine are left to worry about what their doctors will think of them if they complain or fail their treatments. And men are harmed, too. Not only are they less likely to seek help for head pain than women, but once they do, they are less likely to receive a diagnosis of migraine even when presenting to doctors with the same symptoms as a comparable woman.¹⁵ There is also increasing evidence that the cultural stereotype associated with diseases matters when it comes to issues of funding. A recent study found that policymakers increasingly think of *patients* as beneficiaries of research dollars, rather than the disease, the scientific project, or the scientist. As a result, this funding system systematically disadvantages stigmatized diseases that affect patient populations who seem less sympathetic or deserving of tax dollars.¹⁶ This might explain why migraine receives an alarmingly low amount of funding from federal agencies like the National Institutes of Health.¹⁷

How might we reconfigure the cultural resonance of migraine? First, there must be recognition

that the words and representations we use to describe biological processes have social consequences and concrete implications. The language of "sensitivity" might be rooted in a scientific understanding of the nervous system, but it also feminizes the nervous system, eliciting a sense of fragility, instability, emotionality, vulnerability, and distress. These words, combined with advertising images of white women reclining in bed, underscore migraine as a disorder of privilege. Could other words and images serve the same purpose without communicating weakness? As a hypothetical example (and one certainly open for debate!), could a nervous system be on high alert or "vigilant?" A "vigilant" nervous system would augment the senses, which could provide safety and protection under some circumstances, but be damaging when heightened in its extremes. Perhaps images of veterans, many of whom are returning from war with migraine, might be used to begin to interrupt common stereotypes about the kind of person who typically gets migraine. The good news is that the efficacy of these new "frames" for migraine can be tested with vignettes and a good experimental design. A study could help us understand which frames generate public support and which only perpetuate stigma.

Efforts to legitimate migraine require more than biomedical knowledge. Science, with all its power, can't undo ideology. Even neurobiology isn't free from cultural biases. Most Victorians and midcentury doctors also thought of migraine as physiological and it didn't stop them from producing a highly gendered, morally infused portrait of a typical migraine patient. Headache specialists' efforts to reframe migraine as neurobiological may be accurate, but we shouldn't expect a biological model to undo the stigma associated with migraine. Cultural stereotypes of patients are sticky and not so easily dismantled. But they *can* change. Relying on biology won't get people to care about (or fund research on) a particular disease. We have to convince them to care about the people who suffer from it.

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