

The Stigma of Migraine

Stigma leads to loss of status and diminished quality of life.

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Definitions of Stigma

Stigma is an established construct in the social sciences that describes a characteristic, trait, or diagnosis that is used to discredit an individual and leads to prejudice, discrimination, and loss of status.¹ It can also be described as a process that spoils the identity of the stigmatized individual. HIV, depression, and epilepsy are known to be stigmatizing diseases that result in disrupted social relationships, decreased quality of life, and lowered employment rates. Being stigmatized is in itself a negative consequence of disease and also has health implications because it affects the way individuals experiencing stigma seek and access medical care. The lack of social belonging is stressful and incurs negative health outcomes.²⁻⁵

Stigma is different in different diseases. A person with a skin disease may experience it differently than a person with syphilis or one with depression. Whatever the qualities of the stigma, the individual pays a price. Enacted stigma occurs when individuals experience discrimination, for example, from the words of a person of authority, the loss of a social relationship or the loss of employment. Stigma becomes internalized and incorporated into the individual's own feelings about his or her condition and identity, including anticipation about how others might react to it.⁵ Subjective experiences of stigma can be as damaging to health as acts of discrimination and the actual loss of social status.

History of Migraine Stigma

Medical historian, Catherine Foxhall, describes a sea change regarding how migraine was socially perceived, which occurred in the late 18th century.⁶ At that time, a negative perception of migraine began that persists today. Before this historical period, descriptions of and treatments for migraine were as for any other disease as far back as the time of Galen (c. 129 to c. 216/17 CE), who described the disorder as hemicrania. In medical texts from the 16th through 17th centuries, treatments for migraine are described, and again, migraine is treated as any other disease. There is no evidence that people with migraine were looked down upon.

Then, in the late 18th century, people with migraine were represented as privileged, self-absorbed individuals, who used their migraine as an excuse for shirking social duties and avoiding social responsibilities. By the 19th century, migraine was perceived as a weakness of women in the lower socio-economic classes. Physicians caring for patients with migraine were also ridiculed as out of touch, incompetent practitioners who encouraged their patients' neurotic tendencies.⁶ A negative, feminized view of the person with migraine has persisted since, whether migraine was viewed as a psychological defect or as the result of an excitable, feminized brain.⁷

Measurement of Stigma Experienced by Patients With Migraine

The Stigma Scale for Chronic Migraine (SSCI) provides an objective measure that allows systematic study of stigma in migraine. The SSCI is a 24-item questionnaire that asks 13 questions pertaining to internalized stigma and 11 pertaining to enacted stigma. Scores on the SSCI range from 24 to 120. In a study of 511 patients, who were recruited over the internet and had a variety of neurologic diseases including stroke, epilepsy, multiple sclerosis, Parkinson's disease, and motor neuron disease, but not migraine, the mean total score on the SSCI was 42.7 (standard deviation 19.7).⁸ In a clinic-based study of patients with episodic migraine (EM) and chronic migraine (CM), the mean stigma score for EM was 41.7 ± 14.8 , and 54.0 ± 20.2 for CM. In contrast, epilepsy patients had a score of 44.6 ± 16.3 .⁹ For these raw scores, CM was significantly more stigmatized than EM or epilepsy, whereas epilepsy and EM were similar.^{8,9}

Further analysis demonstrated that the ability to work also correlated highly with stigma in epilepsy and in migraine. In the populations studied, patients with CM had the most work-related disability. Removing the question of work-related disability from the questionnaire resulted in similar levels of stigma for CM and epilepsy and slightly less for EM. The ratio of enacted stigma to internalized stigma was similar in all three groups, suggesting the conversion of stigmatizing experiences to low self-esteem was similar across the groups. The relationship of stigma to work

absenteeism was confirmed by a study of respondents who did not necessarily have migraine, showing that stigmatizing attitudes towards persons with migraine increased with work absenteeism, but did not vary by gender.¹⁰

Several other interesting features of the stigma of migraine emerged from the SSCI study. As in the online panel study, gender did not affect stigma scores. Unlike in epilepsy, age, income, and education did not correlate with stigma scores for patients with migraine, suggesting that educational efforts aimed at reducing the stigma of epilepsy have been successful, whereas such efforts do not yet exist for migraine. In the SSCI study, quality of life was much lower in CM than in EM or epilepsy for both the physical and the mental components of the 12-Item Short Form Health Survey (SF-12), suggesting that stigma may have a strong influence on quality of life. Of all the factors studied, the mental component score of the SF-12 correlated most strongly with stigma scores.

This study is somewhat different from a Turkish study that did not use the SSCI to measure migraine stigma, but instead used a 3-item epilepsy stigma scale. In this study, epilepsy was associated with greater stigma than migraine, although quality of life was much worse among migraine patients. The differences between these studies could be related to the severity of illness of the groups studied, the studies' methodology, or cultural differences.¹¹

In her book *Not Tonight: Migraine and the Politics of Gender and Health*, Joanna Kempner uses qualitative methodology to study migraine stigma, referring to this issue as the “legitimacy deficit.”⁷ This issue – legitimacy – pervades the entire book. She finds awareness of this deficit in patients, physicians, scientists, and pharmaceutical companies.

Domains of Stigma for Patients With Migraine

Doctors

Stigma pervades the patient's interaction with the doctor. In online patient groups, physicians are viewed as part of the problem. They habitually psychologize patients, view patients as drug seekers and see patients with migraine as not having a serious disease. Conversely, in a survey of neurologists, 23.8% endorsed that many migraine patients have motivation to maintain their disability, while only 40.1% disagreed with that assertion.¹²

Family

Migraine has a profound effect on the family. In the Chronic Migraine Epidemiology and Outcomes (CaMEO) study, a longitudinal online-based study of 13,064 respondents with migraine, reduced participation in family activities was found in 48.2% to 57.4% of study participants, and correlated with the frequency of migraine attacks (ranging from low-frequency EM to CM). A total of 24.4% of low-frequency EM and 43.9% of CM patients felt their spouses

did not really believe them about their headaches. A total of 14% of spouses of low-frequency EM patients acknowledged that they did not really believe their spouses about their migraine, compared with 22.1% of the spouses of CM patients.¹³

Work

A 2016 survey by a medical insurance provider found that just 22% of employers deemed migraine to be a “serious enough reason for an employee to be absent from work,” lower than for any other reason, including depression, anxiety, stress, the flu, or the common cold.¹⁴ People with migraine must choose which parts of their lives to sacrifice, frequently prioritizing work over others (social, personal, leisure).

People with migraine are discriminated against in qualifying for insurance entitlements based on their diagnosis. That migraine is not included as a qualifying condition for Social Security Disability Insurance (SSDI) exacerbates the existing difficulty in quantifying loss of traditionally noncompensated work such as childcare and housework. To qualify for SSDI, one must compare one's disease-related impairments to those listed for another disease in the Social Security Listing of Impairments (“Blue Book”), making disability determinations more difficult and more capricious than for other diseases. People with employment-related traumatic brain injury resulting in disabling CM incompatible with employment can only qualify for a maximum of 5% of whole person impairment under American Medical Association guidelines for workers compensation. Institutional stigma may force persons with severe migraine to work when they should not, with unreasonable consequences for themselves or their loved ones.

Research

Despite the high prevalence of migraine, stigma also exists toward research of migraine. Funding migraine research by the National Institutes of Health (NIH) is the lowest relative to disease burden among the most impactful diseases (Figure). In 2007, NIH funding per disability-adjusted life-year was \$29 for migraine, \$739 for epilepsy, and \$232 for stroke. On a per-person-with-disorder basis, the individual with migraine received \$0.36 while the stroke patient received \$48.57 and the epilepsy patient received \$35.15. While the last decade has seen some improvement in NIH funding, this gap remains enormous. This reality may discourage academic neurologists from pursuing this specialty, as it could be perceived to be difficult to secure research funding or academic positions. Health care providers may be reluctant to specialize in headache medicine because migraine is not regarded as seriously as other neurologic diseases during training in academic settings and headache disorders

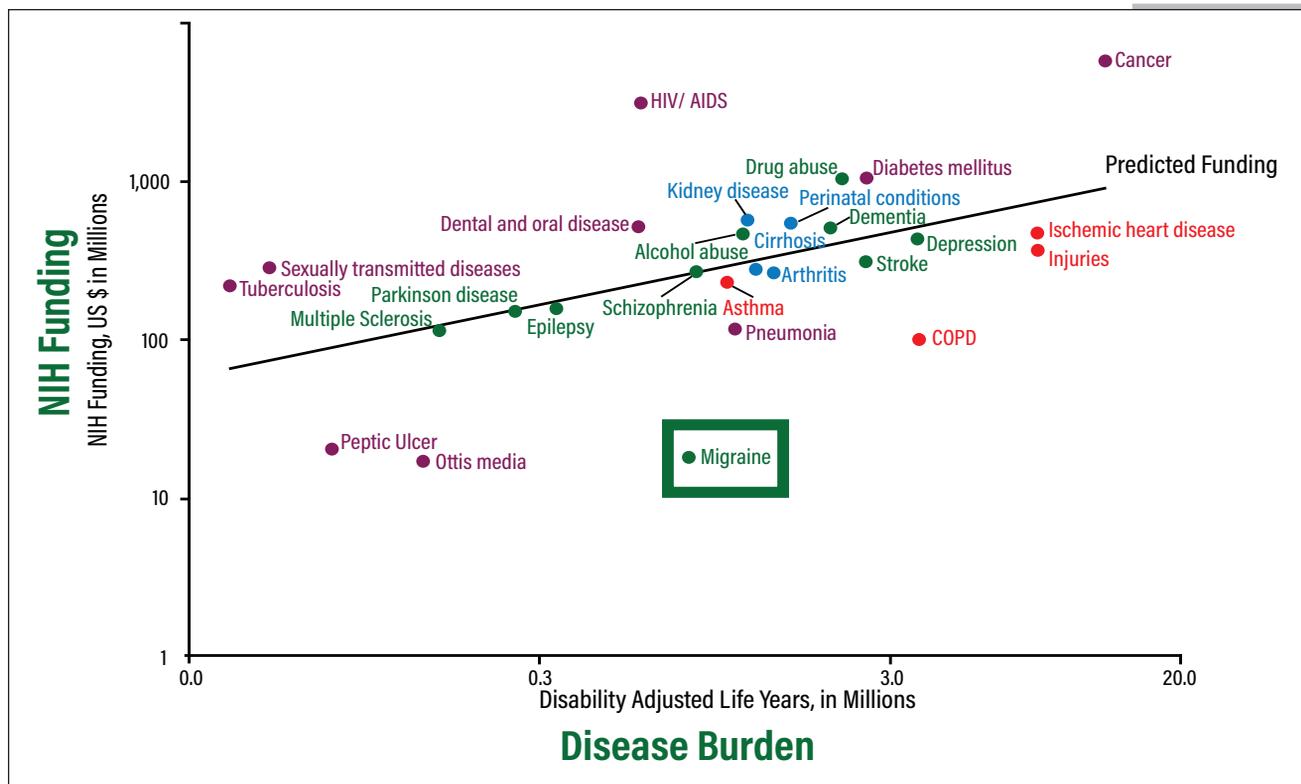


Figure. Funding by the National Institutes of Health in millions of US dollars relative to disease burden shows that migraine is underfunded compared to other disorders that create the same level of disability.

practice might not reimburse as favorably as other neurologic specialties that may rely more heavily on procedural treatments. Lack of investment in migraine research also slows the development of potential treatments. By increasing funding for migraine research, migraine may be able to move forward as a field and patient care may be improved.

Reframing Migraine

A disease frame is the first subconscious perception about that disease. The disease frame has a profound effect on how the public perceives and supports the disease. Reframing has been markedly successful in a number of diseases. HIV was reframed in terms of justice and epidemiologic catastrophe, and persons with HIV infection received respect and research, as well as treatment resources that have dramatically improved the lives of millions of people. Cancer has been reframed and the person with cancer has gone from a victim to a survivor. Autism has been reframed from a rare hopeless disorder to a common condition that affects families profoundly, and there has been a corresponding increase in disease awareness and resources for those affected. All of these diseases, and many more, were successfully reframed through the efforts of advocacy movements by patients and families who physically congregated to advocate for themselves. Online groups have not matched the effects of in-person advocacy.

Migraine is in profound need of such a reframing. The pharmaceutical industry treats migraine as an easy to treat illness of white, middle-class women. Typically, a migraine is seen as affecting a woman who cannot cope. In common parlance, migraine is a metaphor for something irritating, but not serious. In scientific presentations the “migraine brain” cannot handle stress.^{2,16}

Consequences of this include demoralization of patients with migraine and those who care about them, unsuccessful fundraising efforts for research and education, prescription migraine treatments that never reached their market potential, and underfunding of research. Advocacy changes policy toward patients: this includes treatment-related policies from health care systems, provider networks, and physicians. It also increases media interest in a disease.

Future Directions for Reversing the Stigma of Migraine

There are two related problems: the stigmatization of migraine and the lack of migraine-specific disease advocacy. Stigma compounds the burden of illness, becomes internalized, and makes people too demoralized to become advocates. At the same time, history shows that the only way for a disease to be destigmatized is through patient participatory advocacy. Patients with migraine have a stigma similar to other patients with diseases that are not obviously visible

to others. This invisibility makes it more difficult for those who do not suffer from the disease to understand it and in turn makes it more likely that patients will acquiesce to the fear of burdening coworkers or family and keep them from becoming spokespeople and advocates for education about their disease. The participation of people with migraine and their families and friends is critical for migraine advocacy.

Advocacy Is About Reversing Stigma

Advocacy changes policy toward patients, including treatment. Advocacy efforts have reshaped the perceived beneficiaries from the scientists to the patient. Advocacy efforts have promoted measurement of research funding. These shifts have favored conditions in which affected individuals are deemed worthy; for example, breast cancer research is much better funded than lung cancer, although lung cancer has greater impact. Stigmatization translates to loss of funding: “Disease advocacy reshapes funding distributions, changes the perceived beneficiaries of policies, promotes metrics for commensuration, and makes cultural categories of worth increasingly relevant to policymaking.”¹⁷

Next Steps for Creating Advocacy

Marketing theory suggests that diseases can be radically or subtly reframed (or rebranded).¹⁸ Explaining disease causality (pathophysiology) can have profound effects on the way a disease is framed. This is one area where physicians and scientists can have a critical role. However, the field does not have a consensus on a 1- or 3-sentence explanation of migraine pathophysiology. Nonetheless, most explanations have centered on brain hyperexcitability as a part of the explanation of cause of illness, which may reinforce the perception of the person with migraine as having a different, feminized, emotionalized, vulnerable, and damaged brain. A different phrase, “the vigilant brain,” might be preferable.¹⁹

Another avenue for reversing the stigma of migraine may involve the language we choose to use about migraine. There are many ways to describe migraine, but some may be less stigmatizing and more relevant to the experience of the patient. A recent editorial suggests the language choices in the Table below to reduce stigma while better describing the patient’s experience.²⁰

Patient advocacy groups have begun discussing the “migraine elevator speech,” suggesting that patients develop a short speech to explain what migraine is in a way that reduces stigma. Perhaps physicians should begin to consider how they frame migraine for their own patients to reduce the stigma and thus the burden of migraine, even when unable to adequately manage migraine’s symptoms.

Finally, physicians can encourage patients with migraine to participate in migraine advocacy activities, particularly ones where patients congregate, such as walks, runs,

TABLE: CHANGES IN LANGUAGE MAY HELP REDUCE THE STIGMA OF MIGRAINE

Non-stigmatizing language	Stigmatizing language
Try to say this:	Try not to say this:
Disease, condition (sometimes)	Illness, disorder, condition (mostly)
Migraine	Migraines
Migraine	Migraine headache
Person with migraine	Migraineur
Person with migraine	Migraine sufferer
Person with migraine	Migraine personality, migraine-type person
Rebound headache or medication-adaptation headache	Medication-overuse headache
Adapted from Young WB (migraine.com/expert/fighting-for-migraine-with-words/).	

lobbying, education days, and adolescent camps. These should be encouraged over online activities, which do not have the impact of activities where persons with a disease come together with a purpose. Patients with migraine need cheerleaders, and physicians can play that role, or better yet, demonstrate their solidarity through their own participation. ■

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