



Migraine: Stigma in Society

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Published online: 9 February 2019
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Abstract

Migraine is a prevalent disease with a substantial socioeconomic impact. However, stigma affects social attitude toward migraine, accruing additional burden on individuals with migraine and isolating them from a society that should be supporting them.

Purpose of this Review

This review will discuss the following concepts: (1) the emergence of stigma toward migraine and its impact on medical care; (2) internalized stigma among those with migraine and its detrimental effect on quality of life and patient-physician relationships; (3) the structural impact of stigma on research funding, workplace support, and specialized care; and (4) strategies for “rebranding” the disease and alleviating stigma toward migraine.

Recent Findings

Recent literature on condition rebranding offers strategies on how to define and communicate migraine to the public.

Summary

Rebranding of migraine to alleviate societal stigma is paramount. This involves use of unified language, education, and advocacy.

Keywords Stigma · Migraine · Disability · Rebranding · Wellness

Introduction

Migraine affects approximately 12% of Americans in a given year and is a leading cause of global disability [1, 2]. Migraine alone accounts for one-third of global disability-adjusted life years lost (DALYs) and contributes to more than one-half of years lived with disability (YLDs) from all neurological disease [3, 4]. Migraine is associated with substantial healthcare costs and resource utilization, as well as indirect costs from reduced work productivity [5–7]. However, despite its prevalence and socioeconomic impact, the World Health Organization (WHO) notes that only a minority of people with migraine are professionally diagnosed. Furthermore,

appropriate medications are often inaccessible; education for headache disease in formal medical education is lacking, and, most importantly, “illness that could be relieved is not, and burdens, both individual and societal, persist unnecessarily” [8]. An underlying factor for these limitations is stigma. Stigma is a social construct that uses prevailing cultural attitudes to label individuals with adverse attributes and results in stigmatized individuals losing access to social, economic, and political power [9].

We discuss (1) the history of stigma toward migraine, (2) the impact of perceived and internalized stigma among people with migraine, (3) the impact of stigma on structural resources with people with migraine, and (4) proposed steps to alleviate the stigma surrounding migraine.

This article is part of the Topical Collection on *Episodic Migraine*

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History of Stigma in Migraine

Historian Katherine Foxhall traced the origins of stigma attached to migraine [10]. Societal understanding of migraine began with the coining of *hemicrania* by Galen, a Roman Empire era physician who treated migraine as a disease of real

pain [10]. The term emerged as *magryne* in the works of sixteenth century Scottish poet William Dunbar, who not only described the head pain, but also the associated debilitating symptoms and postdrome of migraine [10]. A 1642 recipe book detailed a range of treatments for mild to severe forms of *megrin* [10]. In the 16th and 17th centuries, society legitimized migraine and its accompanying symptoms and understood it as a disease of both men and women [10]. However, in the 18th and 19th centuries, migraine began to become discredited by being associated with “ladies of fashion,” “young female martyrs,” and “mothers in the lower classes of life,” and the diagnosis was put to question [10].

The questioning of migraine as an actual disease starts with the scientific revolution, which transformed previous theories of unseen bodily humors and malaise into the tangible and objective evidence of visible anatomy and pathology. This transformation in public and medical thought may be one reason an invisible disease such as pain or migraine lost its credibility as a legitimate medical disease. This stigma, seeded in the objective lack of migraine manifestations, still plays a role in social understanding of migraine and availability of economic and political resources, as well as in how people with migraine themselves view and treat the disease.

The stigmatizing “gendering” of migraine is an ongoing practice. An estimated 6% of American men have migraine [1]. Despite the prevalence of migraine among men outweighing the prevalence of many other diseases, such as prostate disease or diabetes, migraine is still regarded as a “women’s disease” [11•]. Pharmaceutical marketing exacerbates this stigma: a female subject is up to four times more likely to portray a person with migraine in a pharmaceutical website [11•]. Gendered metaphors appealing to women, such as comparing a treatment to a “spa” experience and gendered messages through visual narratives of women as caretakers, further enhances this notion [11•]. This stigma misconstrues migraine as a disease of women, which perpetuates misdiagnosis and a delay in medical care for men with migraine.

Impact of Internalized Stigma

Internalized stigma, or self-stigma, is the individual cognitive, emotional, and behavioral impact that results from internalizing the adverse attributes attached to stigmatized individuals or diseases by society [12]. Internalized stigma of an illness results when an individual who experiences enacted stigma, or discriminatory societal behavior toward their disease, becomes aware of the negative cultural attitude regarding the disease and, in turn, applies the negative, stigmatized beliefs toward themselves and their illness [12, 13].

There is evidence for internalized stigma among people with chronic and episodic migraine [13, 14••]. Young et al. used a Stigma Scale for Chronic Illness (SSCI), a 24-item

questionnaire assessing patient-perceived internalized and enacted stigma, to compare perceived stigma in patients with epilepsy, chronic migraine, or episodic migraine [14••]. Findings showed that patients with chronic migraine perceived stigma the most, and patients with epilepsy and episodic migraine perceived stigma equally [14••]. Ability to work was the strongest predictor of perceived stigma [14••]. Results from subject responses to fictional vignettes of people with migraine indicated that absenteeism from work, but not gender, was a predictor of stigmatizing attitudes. Together, these studies support the concept of ability to work contributing to internalized stigma.

Studies have demonstrated a correlation between internalized stigma and quality of life among people with mental illness [13, 14••]. Using a 12-item Short Form Health Survey (SF-12), Young et al. showed that people with chronic migraine had a lower perceived quality of life as compared to people with epilepsy or episodic migraine [14••]. These results suggest a correlation between internalized stigma and quality of life among people with migraine.

Studies on perceived stigma in people with mental illness suggest that internalized stigma plays an important role in adherence to treatment, with better medication adherence being associated with lower perceived stigma [15]. “Treatment carryover” conceptualizes the idea that a person with a stigmatized condition, such as migraine, would be more likely to forgo medical treatment as it would result in official labeling and disclosure of the condition, which in turn could lead to discriminatory treatment by society, including by medical providers [16•]. Only 10–15% of patients with migraine see neurologists or headache medicine specialists for care [7]. Among those patients who do seek medical care, patients overall prefer non-pharmacological interventions for treatment, such as behavioral modification, to pharmacologic treatments [17•]. Among pharmacologic options, patients preferred abortive to preventive treatment [17•]. Factors such as medication side effects, cost, dissatisfaction with available pharmacological therapeutic options, and lack of knowledge about the benefit of preventive medication help shape these preferences [17•]. However, internalized stigma of migraine as a “non-medical” condition and treatment carryover may also play a role in patients preferring to forgo preventive treatment for chronic migraine or pharmacological treatment altogether.

Internalized stigma does affect patient-physician relationships. Patients with migraine identified feeling that their physician does not understand the burden of migraine [17•]. These findings may be reflective of stigma enacted by physicians. The Migraine Knowledge, Attitude, and Practice Patterns (MKAPP) Survey assessed the attitudes and approach of neurologists toward migraine [18]. While the majority of neurologists (69%) agreed that migraine is a legitimate brain disease, a substantial remainder of professionals either disagreed or did not have an opinion or response [18]. Moreover, 24% of

neurologists felt that many patients with headache are motivated to maintain their disability [18]. That these attitudes exist even among professionals who are supposed to diagnose and treat migraine underlies the detrimental power of stigma and highlights why patients with migraine may feel a lack of trust in their physicians, condition, or prescribed treatment.

People with migraine also feel that migraine diminishes their perceived credibility and value in the workplace as well as their ability to parent their children [17, 19]. While migraine does have an extensive impact on family, interestingly, data from the Chronic Migraine Epidemiology and Outcomes (CaMEO) study showed that spouses of patients with migraine reported less impact on domains of the parent-child interactions than perceived by patients with migraine [19]. These results resonate with the finding of lowered self-esteem among patients with internalized stigma regarding mental illness [20].

People with migraine are vulnerable to internalized stigma, which can impair their ability to recognize migraine as a disease. Internalized stigma can also impact a person's trust in the medical system and prescribed management as well as their relationships with their workplace and family [17, 19, 20].

Structural Impact of Stigma

Internalized stigma, as well as endorsed stigma, or the expressed agreement with existing stereotypes, and enacted stigma, or individual behavior that discriminates against the

stigmatized, influence structural resources available to people with migraine [16•].

Migraine alone accounts for a third of all global DALYs from neurological diseases [3]. When migraine is compared against epilepsy, another stigmatized neurological condition, patients with chronic migraine were found to have a lower quality of life and higher impact of illness scores [21]. However, research funding for migraine and headache treatment is still lacking compared to epilepsy and other neurological conditions (Fig. 1). According to an analysis by Schwedt and Shapiro, the National Institutes of Health (NIH) vastly underfunds headache disease research [22]. A comparison to the top 10 chronic medical conditions relative to disease burden in 2009 showed that headache disease research warranted more than \$103 million/year but only received \$6.8 to \$13 million/year [22].

Stigma also plays a role in workplace limitations for people with migraine. While migraine is disabling, factors such as flexible workplace ergonomics (for example, adjustments in computer work, lighting, or noise, and odor exposure) could extend an individual's ability to work [23]. Studies have shown that among people with migraine, perceived work-related difficulties, but not more frequent and painful headache, result in higher disability from migraine as rated in the Migraine Disability Assessment (MIDAS) [24]. Appropriate workplace accommodations may therefore result in less disability.

Several factors play a role in restricting workplace accommodations for people with migraine. One is "disclosure carryover," which is the concept that a person with a stigmatized disease,

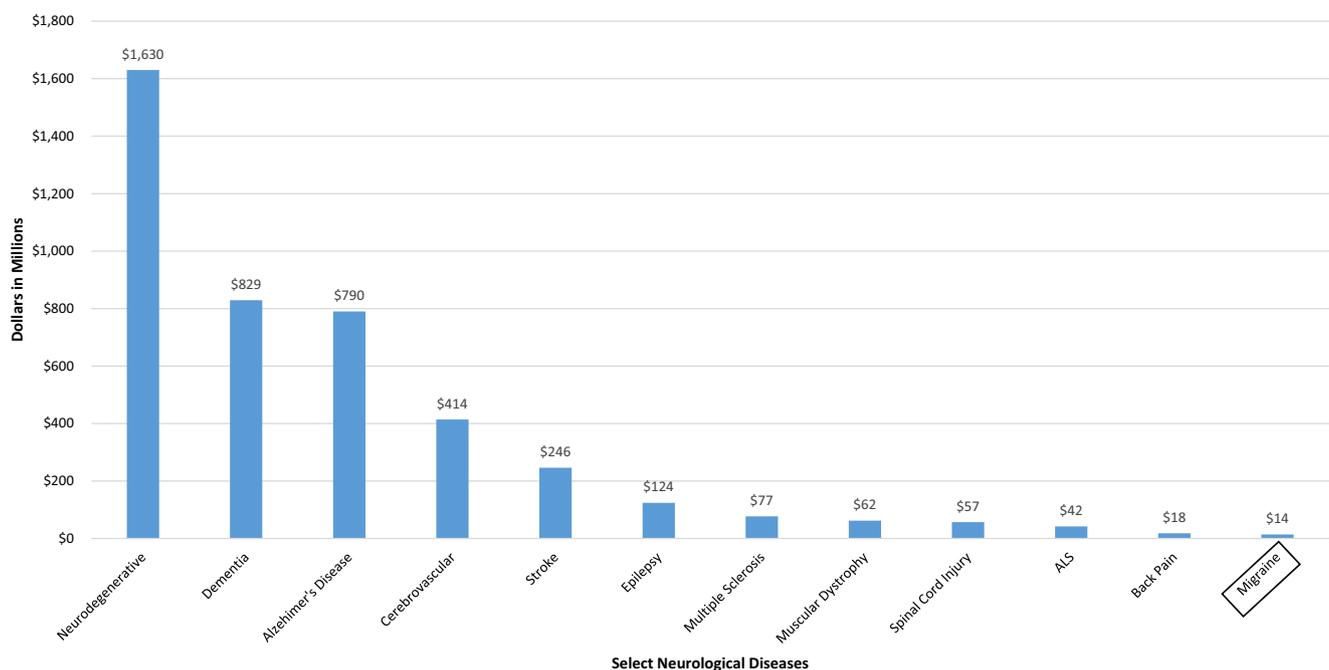


Fig. 1 Migraine is the most common neurological disease and accounts for a third of all global disability-adjusted life years lost from neurological diseases. This graph demonstrates 2018 Estimates of NIH Funding (dollars in millions) for a sample of neurological condition and disease

categories. The graph shows that migraine research is underfunded relative to its frequency and impact on disability. Data downloaded from <https://Report.nih.gov>

such as migraine, may not disclose their condition due to shame or little hope of it being accepted by society [16•]. A 2016 Ipsos survey of 4024 American adults found that more than half of Americans who called out of work due to headache did not reveal to their supervisor that the reason was headache [25]. In addition, people with migraine have difficulty garnering supervisor support in the workplace [25]. Half of all managers surveyed did not consistently accept headache as a reason to call off of work, suggesting endorsed and enacted stigma toward migraine [25]. Continued work is typically preferable to social security disability, which may take as long as 3 years to obtain and cause feelings of isolation and decline in mood state [23]. However, workplace limitations and lack of accommodations to alleviate triggers may force disability on people with migraine.

Stigma, too, may affect the number of professionals who choose to train in headache medicine. Stigma can trigger a desire for social or interpersonal distance from those who are stigmatized [16•]. Perceived, enacted, and endorsed stigma can also cause a multifactorial impact on healthcare training and education [16•]. Currently, there are only 484 United Council for Neurologic Subspecialties (UCNS) certified headache medicine specialists in the USA, with some states without any [26]. The lack of headache medicine specialists directly affects patients' ability to obtain expert diagnoses and management.

Stigma negatively affects structural support for people with migraine, including funding for treatment, workplace accommodations, and access to headache medicine specialists.

Alleviating Stigma

Alleviating stigma toward migraine necessitates condition rebranding. Condition branding involves creating public beliefs regarding the prevalence, outcome, and knowledge of a condition, along with generating a strong emotional association [27•]. Breast cancer, for example, has undergone successful condition branding. There is widespread public awareness of the condition. It motivates strong feelings, which in turn, motivates patient advocacy and private and public sponsorship for condition education and management [27•].

Defining and communicating migraine to the public is difficult. Providers, pharmaceutical companies, and even patients generate conflicting messages and language regarding migraine. The etiology of migraine is complex and, given the nature of unpredictable exacerbations and diverse symptoms, difficult to study. Historically, the cause of migraine has ranged from seizure, to vascular disease, to a psychosomatic condition of an overtaxed nervous system, to disruptions in serotonin, prostaglandins, and endogenous opioids [28]. For this reason, the “brand” has suffered from a lack of a unified profile for public understanding. The first step in rebranding is for the headache medicine community to agree on a unified and focused message of what is migraine.

Communication of migraine is also paramount. Here too, the language frequently used to describe migraine can minimize the condition. For example, the term “migraine headache” limits migraine to only a headache and ignores important accompanying symptoms [29••]. The language can be self-blaming. For example, the term medication overuse headache is judgmental of a patient who has refractory, intractable pain [29••]. The language used can also be self-defining, and may exacerbate internalized stigma. For example, the terms “migraineur” or “migraine sufferer” fail to acknowledge other aspects of the person who has migraine [29••]. Table 1 is an example of how a change in words describing migraine can alleviate stigma.

Educational strategies are an effective means for changing stigma [30]. This involves improved education for the public and people with migraine regarding migraine etiology, prevalence, symptoms, and outcomes. It also involves education among medical professionals in order to recruit more headache medicine specialists, and updating knowledge among all professions regarding treatment guidelines [18]. Reframing stigma as a complex system of interrelated heterogeneous parts can provide continued progress in stigma research [16•].

Advocacy is essential for legitimizing migraine as a disease, which is critical for public and private support. Interpersonal contact helps reduce prejudice [31]. Advocacy through social media and an online presence, as well as through community events and advocacy groups, can target social and public perceptions of migraine on an interpersonal level [32]. Political advocacy for funding toward migraine

Table 1 Using words to alleviate stigma. Adapted from [29]

Say this:	Do not say this:
Disease, condition (sometimes)	Illness, disorder, condition (mostly)
Migraine	Migraines
	Migraine headache
Person with migraine	Migraineur
	Migraine sufferer
	Migraine personality, migraine-type person
Rebound headache or medication adaptation headache	Medication overuse headache
...Medications were ineffective	The patient failed...

research and legal sanctions for workplace accommodations is also important. Experience with other diseases and conditions has demonstrated that physically congregating in a visible way is the most effective way to reverse disease stigma.

Conclusion

Migraine is a prevalent, disabling condition, but access to resources for people with migraine is limited due to stigma in society. The development of stigma may be related to the invisible nature of pain, and the false perception of migraine as a disease of women, reinforced by the emphasis on a feminized concept of the disease by pharmaceutical advertising. Stigma is a complex multilevel system and has both individual and national impacts. Internalized stigma by a person with migraine can result in a lack of trust in the medical system and negatively affects workplace and familial relationships. Enacted and endorsed stigma can influence accessibility to structural resources, such as NIH funding for migraine research, workplace accommodations, and access to specialized care. Rebranding of the condition can alleviate stigma toward migraine. This involves delivering a unified message on the etiology of migraine and using language that represents migraine as a legitimate condition, affecting but not defining an individual. Education and advocacy are critical elements to rebranding migraine and reducing stigma in society.

Funding Information Research partially funded by The Groten Family Fund

Compliance with Ethical Standards

Conflict of Interest Simy K. Parikh and William B. Young declare no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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