Review

Influence of Stigma on the Diagnosis and Treatment of Migraine

Casas-Limón J , Quintas S , López-Bravo A , Alpuente A , Andrés-López A , Castro-Sánchez MV , Membrilla JA , Morales-Hernández Cristian , González-García N , Irimia Pablo *

Posted Date: 24 July 2024

doi: 10.20944/preprints202407.1962.v1

Keywords: migraine; stigma; disability; stereotypes; workplace

Review

Influence of Stigma on the Diagnosis and Treatment of Migraine

Casas-Limón J [1], Quintas S [2], López-Bravo A [3], Alpuente A [4], Andrés-López A [5], Castro-Sánchez MV [6], Membrilla JA [7], Morales-Hernández C [8], González-García N [9] and Irimia P [10,*]

[1] Headache Unit, Hospital Universitario Fundación Alcorcón, Alcorcón, Spain; jcasaslimon@mail.com
[2] Headache Unit, Hospital Universitario de la Princesa & Instituto de Investigación Sanitaria Princesa (IIS-Princesa), Madrid, Spain; sonia.qg@gmail.com
[3] Headache Unit, Hospital Reina Sofía, Tudela, Spain; alba.lopez.bravo@gmail.com
[4] Headache Unit, Hospital Universitario Vall d'Hebron, Barcelona, Spain; alpuente1920@gmail.com
[5] Headache Unit, Hospital Público General de Almansa, Almansa, Spain; albertoanlo91@gmail.com
[6] Headache Unit, Hospital Regional Universitario de Málaga, Málaga, Spain; mvictoriacastrosanchez@gmail.com
[7] Headache Unit, Hospital comarcal Francesc de Borja, Gandía, Spain; membrillaja@gmail.com
[8] Headache Unit, Hospital Universitario de Canarias, La Laguna, Spain; andariell2010@gmail.com
[9] Headache Unit, Hospital Universitario Clínico San Carlos, Madrid, Spain; nurigongar@gmail.com
[10] Headache Unit, Clínica Universitaria de Navarra, Pamplona, Spain; pirimia@unav.es
* Correspondence: pirimia@unav.es

Abstract: several factors contribute to stigma associated with migraine, such as the lack of objective diagnostic tests and biomarkers or traditional gender stereotypes. Patients with migraine can perceive the stigma from different sources: other people (public stigma), organisations (structural stigma) or themselves (internalised stigma), and even neurologists may harbour stigma towards patients with headache. At a social level, repeated migraine attacks lead to restricted participation in work and family life, inducing anxiety, depression and reduced self-esteem. Regarding the workplace, the impact of migraine on their proffesional lives is significant. Individuals who were acquainted with people with migraine at job tended to behave more negatively towards them, and over half of the managers did not consider headache as a valid reason for being absent from work. Effectiveness at work is reduced during a migraine attack, but also because of the interictal symptoms these patients go through. Regarding presenteeism, migraine was the second most expensive disease in the USA, with an annual cost of approximately $240 billion. For all these facts, destigmatisation should take place at the level of healthcare providers, patients and the general population. Implementing educational programmes, training more neurologists in a specialised headache approach, listening to the patients and taking their concerns seriously, or recognizing the disability that the disease causes are strategies that may help minimizing the stigma of migraine.

Keywords: migraine; stigma; disability; stereotypes; workplace

1. Introduction and Historical Perspective

Migraine, a prevalent and disabling neurological condition worldwide, is often accompanied by stigma due to a lack of understanding of its severity and resulting disability [1]. According to findings from the Global Burden of Disease study, migraine is the third leading cause of disability, with a significantly greater impact on middle-aged women [2,3]. Episodic migraine and chronic migraine have an estimated prevalence of 12% and 1.4%-2.2% in the general population, respectively [6,7]. The peak of disability due to migraine is between 20 and 55 years old, which coincides with the peak of migraine prevalence [4].

doi:10.20944/preprints202407.1962.v1

Migraine is associated with substantial economic and social burden and reduced health-related quality of life in affected individuals [5]. The economic burden of chronic migraine, including medical costs and work productivity, is three times higher than that of episodic migraine [8].

Although the quantitative components of quality of life are increasingly recognised and assessed through clinical questionnaires administered to patients with migraine, limited attention has been paid to the qualitative aspects of migraine such as stigma, which refers to a social concept where a characteristic, trait or diagnosis is used to discredit an individual leading to psychosocial repercussions such as prejudice, discrimination, and loss of status [9].

1.1. Migraine Stigma Based on Gender Stereotypes and Underdiagnosis

Throughout history, migraine has been characterized as a predominantly feminine condition associated with 'women of fashion,' 'young female martyrs,' and 'mothers,' leading to questioning its true disease status [10]. It is well-established that migraine is not only more prevalent in women, but also that the associated pain tends to be more severe and longer lasting [11] and both biological and psychological mechanisms, including hormonal changes, are considered as underlying causes.

The perception exists that the elevated occurrence of headaches between women in outpatient clinics may be attributed to the cultural acceptability for women to openly display pain symptoms, whereas men with chronic pain were traditionally perceived as less masculine. This perception, coupled with the historical predominance of male doctors, contributes to women being taken less seriously when seeking medical care for chronic pain. Consequently, women may be unfairly perceived as hysterical and excessively complainant, fostering the misconception that they are unwilling to recover. As a result, they may be erroneously informed that the origin of their pain is psychological rather than somatic. Furthermore, the perception of sexism-related stigma by female patients exacerbates their subjective experience of pain, perpetuating a detrimental cycle [12].

Other factors contribute to stigma associated with migraine. Migraine diagnosis is based on clinical assessment using the International Classification of Headache Disorders criteria [13]. However, the absence of objective diagnostic tests and biomarkers often leads to migraine being unrecognized and misunderstood by society, medical, and scientific communities [14,15]. Consequently, it may be considered a socially invisible disease being vulnerable to stigma [16,17]. Other frequently stigmatized diseases include major depression, schizophrenia, and chronic pain [12].

1.2. Other Types of Stigma in Migraine

Sociologic studies of stigma reveal three major types: public, structural, and internalized. Public stigma encompasses stereotypes recognized by the general public and negative attitudes that may be present. Structural stigma, is when public stigma has repercussions at the political or legal level or in various organizations and groups such as health professional. Finally, internalised stigma where people affected by stigma begin to recognise and believe the negative stereotypes in themselves. In the context of migraine, these stigma types can be foundin the following ways [18]:

1.2.1. Public Stigma in Migraine

People with migraine are often associated with stigmatizing features such as hysteria, hypochondria, pill popping, neurosis, laziness, and difficulty handling stress. Therefore, migraine or headache is used in popular parlance as a metaphor for hard-to-resolve issues. As early as the 11th century, the migraine personality described neurotic women obsessed with housework who exhibited greater facility for nagging their husbands. However, men with migraine were positively described as ambitious and hardworking. To wit, actresses appear more frequently in advertising material for pharmaceutical products targeting migraine and a trend in social networks and fashion magazines which has emerged in recent years depicts women, including famous influencers, in the 'migraine pose', where the fingertips are touching the forehead, so their skin looks tighter. Recently, in the OVERCOME study, the Migraine-Related Stigma (MiRS) questionnaire was created to assess how often the individuals with migraine experienced stigmatizing attitudes from others. The study showed that 31,7% of participants experienced migraine-related stigma often or very often, increasing to 47,5% in those with more than 15 monthly headache days [19].

1.2.2. Structural Stigma in Migraine

In patients with migraine, the most relevant repercussion of structural stigma is the lack of funding for research compared to other neurologic disorders with lower prevalence and, arguably, less impact on the functional capacity of affected individuals. Another dimension of this type of stigma is the limitation of patients with migraine in achieving healthcare contact. Due to the feeling of poor disease management, only 15%–26% of European patients with migraine consult headache professionals and only 2%–6% receive preventive treatment. Regarding healthcare professionals, only 5% of patients with chronic migraine receive the correct diagnosis and treatment. This trend can be justified by not only the underrepresentation of headache disorders during the training of neurologists and other medical specialists but also the fact that migraine is frequently associated with psychiatric conditions, mainly anxiety and depression, which carry their own structural stigma.

1.2.3. Internalised Stigma in Migraine

This type of stigma has been systematically investigated in studies which have used the stigma scale for chronic illness (SSCI) to compare patients with episodic migraine, chronic migraine and epilepsy. One of them revealed that the mean SSCI score was higher (51.6 ± 15.0) in the CM group than in the EM (45.0 ± 13.5) and epilepsy (47.6 ± 15.5) groups, showing that patients with chronic migraine have higher perception of stigma than those with episodic migraine and epilepsy, mainly due to work disability [20]. Conversely, two studies from Turkey [21,22] reported that patients with epilepsy experienced more stigma and that those with migraine primarily experienced enacted stigma. These differences among studies were likely due to cultural and religious backgrounds, perceiving seizures more externally stigmatizing.

2. Psychosocial Impairment in Migraine

Psychosocial impairment, which is defined as mental dysfunction that leads to restricted participation in work, family, or social life [23], is related not only to anxiety and depression but also to reduced self-esteem and internalised stigma experienced by many patients with migraine. At least 48% and 24% of patients with migraine have anxiety and depression, respectively. Depression is associated with absenteeism, presenteeism, activity impairment and perception that their careers have been less successful due to their illness [24].

The most commonly used scales to measure the impact and disability of migraine are HIT-6 [25,26], MIDAS [27], and its paedriatic version PedMIDAS [28]. However, very little attention has been directed towards quantifying the stigma experienced by migraine patients. SSCI is the first tool developed to measure specifically stigma in chronic neurologic diseases. It includes 24 items, with 13 items related to internalized stigma and 11 items related to enacted stigma. Higher scores are strongly associated with psychologic distress, pain, and performance status. However, the SSCI has several limitations and should not be used as a screening tool to differentiate between those patients with and without stigma; the study validating this scale also did not include patients with any type of headache [29].

Psychosocial impairment also impacts family and social relationships. In one study, 53% of patients with migraine missed one social or family activity in the last three months due to migraine. Besides, many patients indicated that migraine had a negative impact on their relationships with their partners and children, asserting that they would have been better partners and parents if they did not have migraine. These findings reflected the internalized stigma experienced by these patients [30,31], which was greater with increasing migraine frequency and was more pronounced in chronic migraine than in episodic migraine.

3. Neurologist's Stigma towards Patients with Migraine

Most neurologists believe that migraine is a disease with a neurobiological basis and that patients with headache are an important component of their practice [32]. However, neurologists also harbour stigma towards patients with headache. In recent surveys, half of neurologists believe there is a stigma against patients with migraine among healthcare professionals. Moreover, 82% of the neurologists reported that treating patients with migraine was challenging and 67% of the neurologists felt that treating patients with migraine was emotionally draining [33,34]. This stigma was also perceived by patients, who reported feeling dismissed by physicians who were perceived not to fully believe their complaints about pain [35].

The number of practicing headache specialists is insufficient considering the high prevalence of migraine and the increasing complexity of its medical approach. A recent study indicated the need for 3,700 headache specialists in the USA [36]. Besides, accurate training in headache is lacking. Several surveys were performed in Europe and the USA to identify the state of specialization in headache diseases among neurology residents [37–41]. Despite the primary limitation of low participation, most of these studies agreed on the lack of a mandatory headache rotation for residents, who usually reported incomplete training and rare involvement in headache investigation. Some reports also identified stigma, with low prestige associated with headache disorders chosen as subspecialty [38,39].

4. Migraine and Stigma in the Workplace

Migraine is the leading cause of disability in adults under 50 and the second leading cause of disability in any age worldwide [8,42–45]. The impact of migraine in the workplace is huge, since the peak of incidence coincides with the years of greatest productivity. The attacks can last from hours to several days, affecting very negatively the patient's professional life [5,46–49].

In a survey of 2000 employees who did not suffer from migraines conducted in the USA, the percentage of people who endorsed that patients with migraine sometimes, often, or very often use their migraine to get out of work commitments was 31%, or as a way to get attention was 27%. Nearly half (45%) felt that migraine should be easily treated, and 36% thought people have migraine because of their own unhealthy behavior [50]. Individuals who were acquainted with migraine sufferers tended to have more negative responses towards them. This stigma was more important if these people had to be absent from work due to their illness [51]. In another survey, over half of the managers did not consider headache as a valid reason for being absent from work, which led to difficulty for migraine patients to seek help at work due to stigma. Consequently, more than half of the patients who were absent from work due to migraine did not disclose it as the reason [52]. A recent study conducted in the workplace at an information technology company with more than 70,000 employees in Japan, revealed that 81% of those who experienced headaches had never seen a doctor. The reasons for not seeking medical help were varied, but one of the most common was the inability to miss work to seek help [53].

4.1. Reduced Work Productivity

Patients report being 46% less effective at work during a migraine attack, and declare headache as the most disabling symptom, followed by difficulty in thinking, photophobia, osmophobia and lastly, nausea [54]. Moreover, migraine affects work productivity even during days without headache, as up to 40% of patients with migraine experience noticeable interictal symptoms such as issues with attention and executive function, processing speed and memory [55–57].

Some patients have a fear that doing tasks that require a certain level of mental effort may trigger or worsen a migraine attack, known as cogniphobia, which can lead to decreased confidence in work-related abilities and negatively impact work and professional performance [58]. In addition to cogniphobia, the unpredictability of migraine attacks is another source of anxiety in patients and may lead to avoiding meetings in the workplace due to fear that a migraine attack will require leaving, significantly reducing overall quality of life [59].

doi:10.20944/preprints202407.1962.v1

4.2. Personal and Economic Impact of Reduced Productivity

The majority of patients with migraine experience career setbacks due to their condition. In a survey including 400 patients, 22% reported that they had to switch careers due to migraine, resulting in reduced opportunities to reach their full potential in their job, which in turn translated into lower socioeconomic status, less medical care, more stressful life events and worsening of migraine. In the same survey, participants were given the option to freely indicate the topics that they felt would best help them to reduce stigma in the workplace; the most common response was awareness and understanding of the disease, followed by support in work environment and flexibility. Eight five percent of the participants stated that their most important desire was for their coworkers to understand that migraine was more than 'just a headache' [46].

The economic impact of migraine-related productivity loss is difficult to calculate because the vast majority of this loss stems from presenteeism associated with the disease. Presenteeism involves working while experiencing migraine symptoms therefore reducing the productivity. Unlike absenteeism, standardized methods assessing the impact of presenteeism are not available. However, the estimated cost incurred by presenteeism is 3–10 times higher than that by absenteeism [60] and increases in parallel with higher frequency of headaches. In a survey conducted in Turkey, patients with chronic migraine, reported an annual average of 3.5 days of absenteeism compared to 87 days of presenteeism, indicating that patients with migraine had reduced productivity by 38% of the year [61]. Similarly, in another study from Turkey, patients with migraine, representing only 2.5% of the entire workforce, accounted for over 45% of all economic loss derived from presenteeism [62]. In a US-based study, the analysis of the economic cost of presenteeism for 22 common diseases in the population revealed that migraine was the second most expensive disease, behind only allergies [51]. Extrapolation of these data suggests that migraine is responsible for an estimated 16% presenteeism in the workplace, with an annual cost of approximately $240 billion [51]. In the above-mentioned Fujitsu study, presenteeism and absenteeism related to migraine patients represented an average annual cost of approximately $2,300 per patient [53].

Although the reasons for presenteeism are multiple and varied, many are derived from migraine-associated stigma. Patients with migraine often report a significant lack of understanding of their condition in the workplace, impaired relationships with colleagues due to headaches, and feelings of guilt about burdening bosses and coworkers [63].

4.3. Supporting People with Migraine and Increasing Productivity

Several approaches can be considered to help and support patients with migraine, starting with workplace accommodations, which have been shown to reduce disability and increase productivity [64]. These accommodations range from using natural light to reducing noise, eliminating aggressive odours, facilitating access to water and services, providing regular breaks, and improving air quality [65].

Heavy workload, very long working hours and rigid schedules have been associated with reduced productivity in patients with migraine; therefore, measures to improve these conditions can help improve the quality of life and productivity of these individuals and could help reducing the stigma [64]. A prospective study with two patients diagnosed with chronic migraine who had failed available pharmacologic treatments, indicated that avoiding night work as well as shift work significantly reduced the number of days with pain and migraine-associated disability while improving quality of life and productivity [66].

The impact of the abovementioned strategies on productive and working activities could help decrease the internalized stigma. However, in most cases these measures are still limited within the company itself and, ironically, migraine patients experience this as their own problem rather than a system failure, which could lead to worsening internalized stigma [18]. Thus, it is important to encourage and generalize these adaptations to improve the quality of life of patients with migraine. In this context, healthcare professionals can help by informing patients about measures that can be implemented in the workplace and providing recommendations and messages of empowerment and self-determination, which have been shown to be the best approach to break down stigma in contrast to messages of pity, akin to what has been demonstrated in other stigmatized diseases such as psychiatric disorders [67].

Several studies have reported the efficacy of different workplace educational programmes in increasing the productivity of patients with migraine [65,68–71] and decreasing the stigma [59]. The main goal of these programmes is to raise awareness of migraine and break the stigma, providing support for people with migraine by improving relationships at work through education [68]. Companies should develop global and centralized strategies to avoid discriminatory issues and other negative consequences.

The Spanish Postal Service developed an educational programme for migraine patients in the workplace. As part of the programme, a survey was sent to all employees and those who reported headaches were offered medical consultation. Those who met the migraine criteria were offered health education and specific treatment for the disease, including targeting attacks as well as preventive treatment if necessary. At the end of the 7-month study, work absences were reduced by 53% and productivity on days worked with migraine attack increased from 59% to 94.8%, which reduced the cost of migraine-related productivity loss by almost 90%[68]. Prospective studies in other countries also showed that these interventional approaches reduced absenteeism, improved productivity, and reduced migraine-associated costs [53,69–71]. Economic return was 5 times (490%) greater than the investment made per patient in a study in Switzerland [70] and up to 32 times in the Japanese study [53]. The latter study also revealed that the educational programme improved understanding and awareness of the impact of migraine on the lives of affected individuals and achieved a change of attitude towards colleagues with migraine in 83% of the participants who did not have headaches, thereby addressing two of the most commonly raised issues by patients: to be understood and to be supported [53].

5. Strategies to Minimise Stigma of Migraine

Changing the social perception of migraine is urgently needed. Destigmatisation should take place at the level of healthcare providers, patients, and the general population. Strategies to minimize stigma of medical conditions are commonly categorised into education, contact and protest [18].

As mentioned above in the workplace section of this review, migraine educational programmes have been demonstrated as effective in changing the stigma. This involves improving the acknowledgement of migraine features by the general population and patients with migraine and explaining migraine aetiology, prevalence, symptoms, outcomes and available treatments. Educational programmes may be useful in replacing wrong migraine stereotypes with facts. For example, educational programmes may focus on the idea that migraine is not just a headache by explaining the wide spectrum of symptoms that may be experienced by the patient during a migraine attack or in the interictal period, such as photophobia, sonophobia, nausea, vomiting, dizziness and cognitive or emotional impairment.

Many means such as books, public service announcements, websites, blogs and documentaries can be used to distribute educational programmes. However, close monitoring is necessary to evaluate outcomes in these educational initiatives.

Educational programmes are also cost-effective with demonstrated efficacy in increasing workplace productivity and reducing absences by half, based on the analysis of findings from several prospective cohort studies [46,68].

Other strategies focusing on improving interactions between the individuals of general population and patients with migraine can alleviate stigma at an interpersonal level. Advisory activities such as walks, races and education camps are helpful in making migraine a visible illness, reducing stigma and raising funds for migraine research [10,72]. Meanwhile, community and grassroot efforts are one of the most important approaches to reduce social stigma, based on the findings of outcome studies pertaining to mental illness [73]. However, protest efforts against injustices caused by stigma should be considered; one study found that forced suppression of stereotypes can paradoxically have a rebound effect and increase stereotype activation [67].

Expanding migraine education at the level of healthcare providers is essential to mitigate negative societal attitudes toward people with migraine. More headache specialists are sorely needed for the timely diagnosis and treatment of patients with migraine and to minimise the risk of progression of episodic migraine to chronic migraine. In addition to training more neurologists in a specialised headache approach, increasing migraine education of primary care doctors, neurology residents and fellows is essential [33]. Conversely, patients expect their doctors to listen and take their concerns seriously before offering treatment. The medical expert should be attentive to more than just data collection and the mere pharmacological response [74]. Open-ended questions are an appropriate approach to encourage patients in expressing their personal experiences about migraine in detail. Although not requiring more time, these approaches are linked to higher satisfaction for both patients and providers, increasing the opportunity to offer effective treatment approaches and to decrease internalised stigma [59].

Healthcare professionals should be very supportive of patients who report their feelings on disability caused by migraine at work. Sharing messages of empowerment and self-determination and avoiding those that encourage pity or compassion have been shown as the best approach to reduce stigma [67]. Physicians should also aid patients in continuing working and providing support for favorable conditions in the workplace. In this regard, the coronavirus disease 2019 pandemic contributed to making the workplace more flexible for working from home, an advantage that may be helpful for patients with migraine in the future. Negative attitudes from healthcare professionals towards patients in this context may increase internalised stigma [18].

Regarding the commonly used language in medical practice, certain words and expressions can perpetuate the stigma of migraine. Hence, they should be changed. In 2019, the Coalition for Headache and Migraine Patients published a list establishing what terms patients prefer, recommending the switch from terms such as migraneur and migrainer to ‘person with migraine disease’, as migraine does not define the affected person nor does it make a person different from others simply due to the diagnosis of migraine. Similarly, using the term ‘migraine headaches’ worsens the stigma, as the rest of accompanying symptoms are undervalued; therefore, it is preferable to use ‘migraine disease’ [75]. Physicians should not emphasise the role of trigger management, as the patient may blame themselves every time they experience a migraine attack. Similarly, the term ‘medication overuse’ is recommended to be replaced by medication adaptation; otherwise patients who are simply trying to relieve pain may feel judged by their physicians.

Unfortunately, despite the availability of proper treatment approaches for migraine and the patients’ best efforts, some have to apply for intermittent or permanent disability caused by migraine. Disability legislations vary among countries; however, in general migraine is rarely recognised as a cause of disability, which implies that access to financial assistance due to migraine disability is very limited or absent [46]. In some countries such as the USA, migraine is recognised as a disability and people with migraine have the right to reasonable accomodations in the workplace, such as flexible schedule, possibility to work from home if possible, scent-free environment, optimisation of desk ergonomics and provision of glasses for light sensitivity. However, if medical treatment optimisation and work accommodations are not sufficient in improving the impact of migraine on quality of life during working hours, applying for disability insurance due to migraine is very difficult. Therefore, there is a great need to change legislation to ensure that disability caused by migraine is well-recognised and that patients who need to apply for disability can benefit from financial support. Social perception of working disability due to migraine must change. Instead of blaming individuals for their inability to continue working, it is necessary to raise awareness of the underlying social and structural issues, which can be improved with more education and legislative changes that reflect the real needs of people with migraine.

Finally, most of the studies on stigma in migraine have been conducted in caucasian adult populations with access to medical health insurance; therefore, the means that can be adopted to minimise stigma covered in this article may be useful only in these groups and information on the extent of stigma and its impact in paediatric populations and marginalised groups is lacking [76]. Further research is warranted to expand this knowledge and to minimise stigma in these populations.

6. Conclusions

Stigma can be frequently found in neurologic disorders, especially in migraine. The personal repercussions of stigma in social, family and work spheres are remarkable. Migraine attacks far exceed the headache itself, adding psychologic, gastrointestinal and cognitive symptoms that trigger the fear of a new migraine onset, anticipatory anxiety and hopelessness. Destigmatisation with educational programmes, training for clinicians, changing the work environment and other approaches are necessary to improve disease control and the quality of life of patients with migraine.

Author Contributions: Javier Casas-Limón: conceptualization, writing original draft, methodology, writing review and editing, project administration, validation, visualization. Sonia Quintas: writing review and editing, supervision, validation, visualization, project administration. Alba López Bravo: writing review and editing, supervision, validation, visualization, project administration. Cristian Morales Hernández: writing original draft, writing review and editing. Alberto Andrés López: writing original draft, writing review and editing. Javier A. Membrilla: writing original draft, writing review and editing. Alicia Alpuente Ruiz: writing original draft, writing review and editing. María Victoria Castro Sánchez: writing original draft, writing review and editing. Nuria González García: writing original draft, writing review and editing. Pablo Irimia Sieira: conceptualization, writing review and editing, supervision, validation, visualization, project administration.

Funding: This research received no external funding.

Data Availability Statement: no new data were created.

Acknowledgments: none.

Conflicts of Interest: The authors declare no conflicts of interest.

References

1. Ashina M, Katsarava Z, Do TP, Buse DC, Pozo-Rosich P, Özge A, Krymchantowski AV, Lebedeva ER, Ravishankar K, Yu S, Sacco S, Ashina S, Younis S, Steiner TJ, Lipton RB (2021) Migraine: epidemiology and systems of care. Lancet 397:1485-1495. https://doi.org/10.1016/S0140-6736(20)32160-7.
2. GBD 2021 Nervous System Disorders Collaborators. Global, regional, and nationalburden of disorders affecting the nervous system, 1990-2021: a systematic analysis for the Global Burden of Disease Study 2021. Lancet Neurol. 2024;23:344-381.
3. Steiner TJ, Stovner LJ, Jensen R, Uluduz D, Katsarava Z (2020) Lifting The Burden: the Global Campaign against Headache Migraine remains second among the world's causes of disability, and first among young women: findings from GBD2019. J Headache Pain 21:137. https://doi.org/10.1186/s10194-020-01208-0.
4. Buse DC, Loder EW, Gorman JA, Stewart WF, Reed ML, Fanning KM, Serrano D, Lipton RB (2013) Sex differences in the prevalence, symptoms, and associated features of migraine, probable migraine and other severe headache: results of the American migraine prevalence and prevention (AMPP) study. Headache 53:1278-1299. https://doi.org/10.1111/head.12150.
5. Burch RC, Buse DC, Lipton RB (2019) Migraine: epidemiology, burden, and comorbidity. Neurol Clin 37:631-649. https://doi.org/10.1016/j.ncl.2019.06.001.
6. Natoli JL, Manack A, Dean B, Butler Q, Turkel CC, Stovner L, Lipton RB (2010) Global prevalence of chronic migraine: a systematic review. Cephalalgia 30:599-609. https://doi.org/10.1111/j.1468-2982.2009.01941.x.
7. Buse DC, Manack AN, Fanning KM, Serrano D, Reed ML, Turkel CC, Lipton RB (2012) Chronic migraine prevalence, disability, and sociodemographic factors: results from the American migraine prevalence and prevention study. Headache 52:1456-1470. https://doi.org/10.1111/j.1526-4610.2012.02223.x.
8. Lipton RB, Manack Adams A, Buse DC, Fanning KM, Reed ML (2016) A comparison of the chronic migraine epidemiology and outcomes (CaMEO) study and American migraine prevalence and prevention (AMPP) study: demographics and headache-related disability. Headache 56:1280-1289. https://doi.org/10.1111/head.12878.
9. Young WB, Park JE, Tian IX, Kempner J (2013) The stigma of migraine. PLOS ONE 8:e54074. https://doi.org/10.1371/journal.pone.0054074.
10. Parikh SK, Young WB (2019) Migraine: stigma in society. Curr Pain Headache Rep 23:8. https://doi.org/10.1007/s11916-019-0743-7.
11. Vetvik KG, MacGregor EA (2017) Sex differences in the epidemiology, clinical features, and pathophysiology of migraine. Lancet Neurol 16:76-87. https://doi.org/10.1016/S1474-4422(16)30293-9.
12. Perugino F, de Angelis V, Pompili M, Martelletti P (2022) Stigma and chronic pain. Pain Ther 11:1085-1094. https://doi.org/10.1007/s40122-022-00418-5.

13. Arnold M (2018) Headache classification committee of the international headache society (HIS) the international classification of headache disorders. Cephalalgia 38:1-211. https://doi.org/10.1177/0333102417738202
14. Shapiro RE, Lipton RB, Reiner PB (2014) EHMTI-0313. Factors influencing stigma towards persons with migraine. J Headache Pain 15:E36. https://doi.org/10.1186/1129-2377-15-S1-E36.
15. Shapiro RE, Reiner PB (2013) Stigma towards migraine. Cephalalgia 33:17.
16. Lonardi C (2007) The passing dilemma in socially invisible diseases: narratives on chronic headache. Soc Sci Med 65:1619-1629. https://doi.org/10.1016/j.socscimed.2007.07.007.
17. Shapiro RE (2020) What will it take to move the needle for headache disorders? an advocacy perspective. Headache 60:2059-2077. https://doi.org/10.1111/head.13913.
18. Parikh SK, Kempner J, Young WB (2021) Stigma and migraine: developing effective interventions. Curr Pain Headache Rep 25:75. https://doi.org/10.1007/s11916-021-00982-z.
19. Shapiro RE, Nicholson RA, Seng EK, Buse DC, Reed ML, Zagar AJ, Ashina S, Muenzel J, Hutchinson S, Pearlman EM, Lipton RB (2024) Migraine-related stigma and its relationship to disability, interictal burden, and quality of life. Neurology 2024;102:e208074. https://doi.org/10.1212/WNL.0000000000208074
20. Martínez-Fernández A, Rueda Vega M, Quintas S, de Toledo Heras M, Díaz de Terán J, Latorre González G, Trabajos García O, Vivancos Mora J, Gago-Veiga AB (2020) Psychosocial repercussion of migraine: is it a stigmatized disease? Neurol Sci 41:2207-2213. https://doi.org/10.1007/s10072-020-04332-6.
21. Basoglu Koseahmet F, Polat B, Gozubatik-Celik RG, Baytekin I, Soylu MG, Ceyhan Dirican A, Ozturk M (2022) An invisible cause of disability: stigma in migraine and epilepsy. Neurol Sci 43:3831-3838. https://doi.org/10.1007/s10072-022-05888-1.
22. Aydemir N, Özkara C, Ünsal P, Canbeyli R (2011) A comparative study of health related quality of life, psychological well-being, impact of illness and stigma in epilepsy and migraine. Seizure 20:679-685. https://doi.org/10.1016/j.seizure.2011.06.017.
23. Raggi A, Giovannetti AM, Quintas R, D'Amico D, Cieza A, Sabariego C, Bickenbach JE, Leonardi M (2012) A systematic review of the psychosocial difficulties relevant to patients with migraine. J Headache Pain 13:595-606. https://doi.org/10.1007/s10194-012-0482-1.
24. Pearl TA, Dumkrieger G, Chong CD, Dodick DW, Schwedt TJ (2020) Impact of depression and anxiety symptoms on patient-reported outcomes in patients with migraine: results from the American registry for migraine research (ARMR). Headache 60:1910-1919. https://doi.org/10.1111/head.13911.
25. Kosinski M, Bayliss MS, Bjorner JB, Ware JE Jr., Garber WH, Batenhorst A, Cady R, Dahlöf CG, Dowson A, Tepper S (2003) A six-item short-form survey for measuring headache impact: the HIT-6. Qual Life Res 12:963-974. https://doi.org/10.1023/a:1026119331193.
26. Rendas-Baum R, Yang M, Varon SF, Bloudek LM, DeGryse RE, Kosinski M (2014) Validation of the headache Impact Test (HIT-6) in patients with chronic migraine. Health Qual Life Outcomes 12:117. https://doi.org/10.1186/s12955-014-0117-0.
27. Stewart WF, Lipton RB, Dowson AJ, Sawyer J (2001) Development and testing of the migraine disability assessment (MIDAS) questionnaire to assess headache-related disability. Neurology 56:S20-S28. https://doi.org/10.1212/wnl.56.suppl_1.s20.
28. Hershey AD, Powers SW, Vockell AL, LeCates S, Kabbouche MA, Maynard MK (2001) PedMIDAS: development of a questionnaire to assess disability of migraines in children. Neurology 57:2034-2039. https://doi.org/10.1212/wnl.57.11.2034.
29. Rao D, Choi SW, Victorson D, Bode R, Peterman A, Heinemann A, Cella D (2009) Measuring stigma across neurological conditions: the development of the stigma scale for chronic illness (SSCI). Qual Life Res 18:585-595. https://doi.org/10.1007/s11136-009-9475-1.
30. Lipton RB, Bigal ME, Kolodner K, Stewart WF, Liberman JN, Steiner TJ (2003) The family impact of migraine: population-based studies in the USA and UK. Cephalalgia 23:429-440. https://doi.org/10.1046/j.1468-2982.2003.00543.x.
31. Buse DC, Scher AI, Dodick DW, Reed ML, Fanning KM, Manack Adams A, Lipton RB (2016) Impact of migraine on the family: perspectives of people with migraine and their spouse/domestic partner in the CaMEO study. Mayo Clin Proc 91:596-611. https://doi.org/10.1016/j.mayocp.2016.02.013.
32. Lipton RB, Bigal ME, Rush SR, Yenkosky JP, Liberman JN, Bartleson JD, Silberstein SD (2004) Migraine practice patterns among neurologists. Neurology 62:1926-1931. https://doi.org/10.1212/wnl.62.11.1926.
33. Zubair AS, Sico JJ, Kuruvilla DE (2021) Presence of stigma in the treatment of patients with migraine among neurologists. Pain Med 22:2135-2138. https://doi.org/10.1093/pm/pnaa465.
34. Begasse de Dhaem O, Burch R, Rosen N, Shubin Stein K, Loder E, Shapiro RE (2020) Workforce gap analysis in the field of headache medicine in the United States. Headache 60:478-481. https://doi.org/10.1111/head.13752.
35. Gago-Veiga AB, Santos-Lasaosa S, Viguera Romero J, Pozo-Rosich P (2018) Are neurology residents interested in headache? Neurologia 33:1-7. https://doi.org/10.1016/j.nrl.2016.04.013.

36. Ahmed ZA, Faulkner LR (2016) Headache education in adult neurology residency: A survey of program directors and chief residents. Headache 56:871-877. https://doi.org/10.1111/head.12822.
37. Kommineni M, Finkel AG (2005) Teaching headache in America: survey of neurology chairs and residency directors. Headache 45:862-865. https://doi.org/10.1111/j.1526-4610.2005.05154.x.
38. Beltramone M, Redon S, Fernandes S, Ducros A, Avouac A, Donnet A (2022) The teaching of headache medicine in France: a questionnaire-based study. Headache 62:1177-1186. https://doi.org/10.1111/head.14395.
39. Kristoffersen ES, Faiz KW, Winsvold BS (2019) Neurology residents' knowledge of the management of headache. Cephalalgia 39:1396-1406. https://doi.org/10.1177/0333102419847973.
40. Kristensen MGH, Do TP, Pozo-Rosich P, Amin FM (2022) Interest in and exposure to headache disorders among neurology residents in Denmark: a nationwide cross-sectional survey. Acta Neurol Scand 146:568-572. https://doi.org/10.1111/ane.13681.
41. Do TP, Dømgaard M, Stefansen S, Kristoffersen ES, Ashina M, Hansen JM (2022) Barriers and gaps in headache education: a national cross-sectional survey of neurology residents in Denmark. BMC Med Educ 22:233. https://doi.org/10.1186/s12909-022-03299-6.
42. Peres MFP, Queiroz LP, Rocha-Filho PS, Sarmento EM, Katsarava Z, Steiner TJ (2019) Migraine: a major debilitating chronic non-communicable disease in Brazil, evidence from two national surveys. J Headache Pain 20:85. https://doi.org/10.1186/s10194-019-1036-6.
43. GBD 2016 Headache Collaborators (2018) Global, regional, and national burden of migraine and tension-type headache, 1990-2016: a systematic analysis for the global burden of disease study 2016. Lancet Neurol 17:954-976. https://doi.org/10.1016/S1474-4422(18)30322-3.
44. Steiner TJ, Stovner LJ, Vos T, Jensen R, Katsarava Z (2018) Migraine is first cause of disability in under 50s: will health politicians now take notice? J Headache Pain 19:17. https://doi.org/10.1186/s10194-018-0846-2.
45. Link BG, Phelan JC (2006) Stigma and its public health implications. Lancet 367:528-529. https://doi.org/10.1016/S0140-6736(06)68184-1.
46. Begasse de Dhaem O, Sakai F (2022) Migraine in the workplace. eNeurologicalSci 27:100408. https://doi.org/10.1016/j.ensci.2022.100408.
47. Lipton RB, Stewart WF, von Korff M (1997) Burden of migraine: societal costs and therapeutic opportunities. Neurology 48:S4-S9. https://doi.org/10.1212/wnl.48.3_suppl_3.4s.
48. Kim BK, Cho SJ, Kim CS, Sakai F, Dodick DW, Chu MK (2021) Disability and economic loss caused by headache among information technology workers in Korea. J Clin Neurol 17:546-557. https://doi.org/10.3988/jcn.2021.17.4.546.
49. Henry P, Auray JP, Gaudin AF, Dartigues JF, Duru G, Lantéri-Minet M, Lucas C, Pradalier A, Chazot G, El Hasnaoui A (2002) Prevalence and clinical characteristics of migraine in France. Neurology 59:232-237. https://doi.org/10.1212/wnl.59.2.232.
50. Shapiro RE, Araujo AB, Nicholson RA, Reed ML, Buse DC, Ashina S Jaffe DH, Cambron-Mellott M, Li VW, Zagar A, Pearlman EM (2019) OR15: stigmatizing attitudes about migraine by people without migraine: results of the OVERCOME study. Headache J Head Face Pain 59:14-16.
51. Allen D, Hines EW, Pazdernik V, Konecny LT, Breitenbach E (2018) Four-year review of presenteeism data among employees of a large United States health care system: a retrospective prevalence study. Hum Resour Health 16:59. https://doi.org/10.1186/s12960-018-0321-9.
52. Employees hide headaches, migraines from supervisors. (2018). Internet. 2018.AvailableRetrieved fromhttps://www.reuters.com/brandfeatures/excedrin/employees-hide-headaches-migraines-from-supervisors.
53. Sakai F, Igarashi H, Yokoyama M, Begasse de Dhaem O, Kato H, Azuma Y, Koh R, Phillips H, Singh N, Craven A, Dodick DW, Miyake H (2023) Diagnosis, knowledge, perception, and productivity impact of headache education and clinical evaluation program in the workplace at an information technology company of more than 70,000 employees. Cephalalgia 43:3331024231165682. https://doi.org/10.1177/03331024231165682.
54. Gerth WC, Carides GW, Dasbach EJ, Visser WH, Santanello NC (2001) The multinational impact of migraine symptoms on healthcare utilisation and work loss. Pharmacoeconomics 19:197-206. https://doi.org/10.2165/00019053-200119020-00006.
55. D'Amico D, Grazzi L, Curone M, Di Fiore P, Proietti Cecchini A, Leonardi M, Scaratti C, Raggi A (2015) Difficulties in work activities and the pervasive effect over disability in patients with episodic and chronic migraine. Neurol Sci 36:9-11. https://doi.org/10.1007/s10072-015-2130-4.
56. Shimizu T, Sakai F, Miyake H, Sone T, Sato M, Tanabe S, Azuma Y, Dodick DW (2021) Disability, quality of life, productivity impairment and employer costs of migraine in the workplace. J Headache Pain 22:29. https://doi.org/10.1186/s10194-021-01243-5.
57. Begasse de Dhaem O, Robbins MS (2022) Cognitive impairment in primary and secondary headache disorders. Curr Pain Headache Rep 26:391-404. https://doi.org/10.1007/s11916-022-01039-5.

58. Seng EK, Klepper JE (2017) Development of the cogniphobia scale for headache disorders (CS-HD): A pilot study. Psychol Assess 29:1296-1301. https://doi.org/10.1037/pas0000432.
59. Estave PM, Beeghly S, Anderson R, Margol C, Shakir M, George G, Berger A, O'Connell N, Burch R, Haas N, Powers SW, Seng E, Buse DC, Lipton RB, Wells RE (2021) Learning the full impact of migraine through patient voices: a qualitative study. Headache 61:1004-1020. https://doi.org/10.1111/head.14151.
60. Goetzel RZ, Long SR, Ozminkowski RJ, Hawkins K, Wang S, Lynch W (2004) Health, absence, disability, and presenteeism cost estimates of certain physical and mental health conditions affecting U.S. employers. J Occup Environ Med 46:398-412. https://doi.org/10.1097/01.jom.0000121151.40413.bd.
61. Selekler HM, Gökmen G, Alvur TM, Steiner TJ (2015) Productivity losses attributable to headache, and their attempted recovery, in a heavy-manufacturing workforce in Turkey: implications for employers and politicians. J Headache Pain 16:96. https://doi.org/10.1186/s10194-015-0579-4.
62. Selekler MH, Gökmen G, Steiner TJ (2013) Productivity impact of headache on a heavy-manufacturing workforce in Turkey. J Headache Pain 14:88. https://doi.org/10.1186/1129-2377-14-88.
63. Constance KC (2002) Perceptions and Needs of Patients with Migraine. J Fam Pract. 51(2): 142–147.
64. Borkum J, Evans RW (2014) Disability and chronic migraine. Headache 54:719-725. https://doi.org/10.1111/head.12339.
65. Begasse de Dhaem O, Gharedaghi MH, Bain P, Hettie G, Loder E, Burch R (2021) Identification of work accommodations and interventions associated with work productivity in adults with migraine: a scoping review. Cephalalgia 41:760-773. https://doi.org/10.1177/0333102420977852.
66. Sandoe CH, Sasikumar S, Lay C, Lawler V (2019) The impact of shift work on migraine: A case series and narrative review. Headache 59:1631-1640. https://doi.org/10.1111/head.13622.
67. Corrigan PW (2016) Lessons learned from unintended consequences about erasing the stigma of mental illness. World Psychiatry 15:67-73. https://doi.org/10.1002/wps.20295.
68. Vicente-Herrero T, Burke TA, Laínez MJ (2004) The impact of a worksite migraine intervention program on work productivity, productivity costs, and non-workplace impairment among Spanish Postal Service employees from an employer perspective. Curr Med Res Opin 20:1805-1814. https://doi.org/10.1185/030079904X10151.
69. Parker C, Waltman N (2012) Reducing the frequency and severity of migraine headaches in the workplace: implementing evidence-based interventions. Workplace Health Saf 60:12-18. https://doi.org/10.1177/216507991206000103.
70. Schaetz L, Rimner T, Pathak P, Fang J, Chandrasekhar D, Mueller J (2020) Impact of an employer-provided migraine coaching program on burden and patient engagement: results from interim analysis. Neurology 94:1126.
71. Lantéri-Minet M, Allain H, Nachit-Ouinekh F, Bentué-Ferrer D, Gilbert P, Schück S, El Hasnaoui A, Comité d'Orientation National (2004) Noemie: un Observatoire de la Migraine en Entreprise. Rev Neurol (Paris) 160:928-934. https://doi.org/10.1016/s0035-3787(04)71074-7.
72. Vilanilam GK, Badi MK, Meschia JF (2018) Destigmatizing migraine. Cureus 10:e2711. https://doi.org/10.7759/cureus.2711.
73. Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rüsch N (2012) Challenging the public stigma of mental illness: a meta-analysis of outcome studies. Psychiatr Serv 63:963-973. https://doi.org/10.1176/appi.ps.201100529.
74. Gross E, Ruiz de la Torre E, Martelleti P (2023) The migraine stigma kaleidoscope view. Neurol Ther. 2023 Jun; 12(3): 703–709. https://doi.org/10.1007/s40120-023-00456-x
75. CHAMP releases headache and migraine disease language and image guide-coalition for headaeche and migraine patients Internet. https://headachemigraine.org/headache-and-migraine-disease-language-and-image-guide/.
76. Allen H, Wright BJ, Harding K, Broffman L (2014) The role of stigma in access to health care for the poor. Milbank Q 92:289-318. https://doi.org/10.1111/1468-0009.12059.