



The Migraine Stigma Kaleidoscope View

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ABSTRACT

The stigma of migraine, despite an impressive body of data on the epidemiological of migraine and the associated disability, burden and cost of migraine to patients, has not been fully evaluated as an important factor in the chronicization of the disease and social isolation of the patient. In this commentary, we present three points of view. From the point of view of a European advocacy body active in the field of migraine medicine, actions to improve the perception of migraine within the community regarding the stigma for people with migraine are presented at the personal, relational and occupational levels. From the point of view of a clinician who is an expert on migraine, proposals are made for treatment and rehabilitation paths specifically dedicated to the reintegration of these individuals into social contexts.

Keywords: Migraine; Stigma; Patient; Chronization; Advocacy; Workplace; Education; HCPWGs, Public health; Multimodal approach

It is not reality that is fixed but the vision of it that is changeable. (Luigi Pirandello (1867-1936), Nobel Prize 1934).

Key Summary Points

The World Health Organization's definition of stigma includes the terms "mark of shame," "disgrace" or "disapproval."

Individuals affected by migraine are vulnerable to stigma due to the reaction of others.

Stigma affects social relationships, clinical settings and workplace.

The Migraine Patients' Association advocates awareness of and public action on stigma.

Management of migraine by clinical experts should go beyond the mere prescription of drugs.

A multimodal approach to remove stigma in migraine individuals should be implemented.

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THE PATIENT'S PERSPECTIVE (ELENA GROSS)

The Headache that Doesn't Exist

It is 1994. The Internet isn't a 'thing' yet, so I'm sitting on the couch in our living room with some kindergarten friends, clutching a pillow in excitement and glued to the television. Though it's normally a special treat reserved for rainy Sunday afternoons, my parents have given in to our demands to watch *Pünktchen und Anton* yet again. Like little sponges we soak up the morals and details of the story, as we watch the German children's movie for what must be the tenth time. At one point, the protagonist, Anton, asks his friend Pünktchen's dad what's wrong with her mum—a thin, middle-class, middle-aged housewife who spends most of the time in bed with her eyes covered. 'She gets migraines', the dad says. When Anton then asks him what a migraine is, his response is clear: 'Migraines?! Migraines are headaches that don't exist.' And for the following decade that was what we believed.

Fast forward a few years and I'm woken up in the early hours by a throbbing pain that radiates along the right side of my head, piercing my eyes and cheekbones. I'm in Fort Worth, Texas, on a 6-month school exchange. Sleep is impossible. Texas is a dry, dusty place, so maybe this is an exaggerated form of hay fever? I try to get up to take some antihistamines, but movement makes the pain much worse so I opt for painkillers from my nightstand instead. I feel very unwell, but in a way that feels unfamiliar. There's no one around to ask, so I just decide it must be allergies.

Only 2 weeks later I feel weak and sick again, but this time I'm aware enough to know my symptoms are not being caused by my allergies. My teacher is examining my pale face: 'Elle, are you ok? What's wrong?' *Am* I okay? I don't think so. My brain can't function, the neon light above is far too bright and my muscles are like jelly. But the strongest sensation is one of sudden, overwhelming fatigue. What is wrong with me? Stumbling through the classroom

door, guided by my confused teacher, all I can think about is when this feeling might end.

A few months later, back in my parent's house in Germany, I wake up in the early hours, sweating. The headache has returned, and the pain is worse than ever. I feel like I can't move. There are no painkillers in sight. Gathering all my strength, I attempt to get out of bed, but with every move, what feels like waves of burning liquid swirl through the right side of my skull. Now desperate for pain relief, I crawl to the bathroom, where I manage to pull myself up using the sink, only to find the pills are out of reach. Without the prospect of rescue, I break down. My parents find me crying on the bath mat. For the last 2 years, my dad has been very dismissive of my 'whining' about a 'mere' headache, but my mum decides it's time to take it seriously.

'Have you had an EEG [electroencephalogram] yet? What about an MRI [magnetic resonance imaging] scan?' asks my local GP. I shake my head. The headaches' increasing severity and one-sided nature certainly make a tumor a feasible explanation, if also a scary one. We decide that an EEG is in order. Some electrodes are glued to my scalp to monitor electrical charges in my brain for any irregularities. As I watch the squiggly lines appear on the paper spewing out of the EEG machine, I grow increasingly concerned about what they're going to tell us. But the neurologist says it's all normal. Phew.

Next stop, an MRI scan. No gel this time, just some over-sized magnet-safe pyjamas and a rather noisy tunnel. And it's more good news as a tumor is firmly ruled out. Tests now complete, the doctors can find nothing obvious physically to cause the headaches, so the logical next step is to send me to a psychotherapist.

'Do you feel unhappy?' The question comes from the woman on the other side of a massive wooden desk and with an expression that's supposed to convey understanding, empathy, concern and kindness all at once. 'Well,' I say, 'I'm pretty unhappy when I have these terrible headaches. I'm missing out on school work and seeing my friends and they come at the most inconvenient times. Plus, I have absolutely no control over them, which makes it even worse.'

Excluding the headaches, I'm okay.' The word 'school' is clearly a trigger, because after making some notes she asks if I am having problems at school. I shake my head. She probes further: 'What are your weakest subjects?' 'Geography and French, B+ and B,' I explain. Her advice? To devote more resources and time to these subjects. And with that I am released, this time feeling even more hopeless.

But I keep looking for answers. This time I turn to 'Dr. Google'—luckily for us the Internet is now a 'thing'—where an intensive search for 'one-sided headache' and 'light sensitivity' throws up thousands of promising hits. Chatting to my mum, she recalls her mother having similar headaches when she was younger, although no one ever took her seriously. Eureka. Soon, a visit to a specialist clinic proves that Pünktchen's dad was wrong: migraines *do* exist.

Ultimately, my migraines turned from episodic to chronic (meaning severe). I was in pain at least 50% of the time, despite trying everything from pharmacological to alternative treatments, and seeing every specialist I could find. It was a constant struggle of teachers thinking I was missing school because of not caring, my friends thinking I was unreliable—they stopped inviting me—and me missing out on the most fun things and experiences that one is supposed to make in one's youth. Even when I was older and working in migraine research in a neurology department, my colleagues thought I was faking being unwell to skip working. As experts, I always thought they should have known better. While migraines do exist, they seemed to be the unwanted child of neurology—despite its prevalence few seemed to take them (and in turn me) seriously.

THE PATIENTS ADVOCACY ASSOCIATION PERSPECTIVE (ELENA RUIZ DE LA TORRE)

Is There Stigma in Migraine?

The European Migraine and Headache Alliance (EMHA) is an umbrella organization

representing over 33 patient advocacy organizations from 23 countries in Europe.

Since EMHA was founded in 2005, "Stigma" is a term that has showed up again and again when affected people refer to their neurological disease. Many aspects around migraine need to be organized.

Migraine is a neurological incapacitating disease which affects one in seven people in the world [1]. It's a heavy burden and people with migraine face enormous misunderstanding of their condition from family to friends, and also healthcare professionals, employers and/or politicians. There is a widespread conviction in society that migraine is just a plain headache and that those of us who suffer from migraine have very little resistance or are using it as an excuse. Nothing could be further from the truth. Those of us who live with migraine prove throughout our lives to be capable of operating on a level with those who do not suffer from this terrible pain [2, 3]. There is currently no cure for migraine; its treatment is symptomatic, and we are now beginning to see new preventive treatments [4]. Since migraine is an invisible disease and is not seen as a direct risk to people's lives, many people do not receive the support that is clearly needed. Patients feel they are ignored, poorly treated and poorly understood when they go to the doctor, and new treatments are not easy to access in many countries. Most of the economic burden is a socio-economic burden that payers, regulatory bodies and health technology assessment bodies don't take into a consideration [5]. Migraine is not a priority for healthcare policy-makers and although the costs—especially the indirect costs—are very high, it's mostly the ones affected by migraine who pay for it.

It could be said that despite the incredible scientific advances in migraine over the past 20 years, societal perceptions about the condition have not changed. It is still viewed as just a headache, and the burdens of living with migraine are not appreciated. This means that policy-makers do not give the condition the priority it deserves, and people affected by the condition do not get the empathy and understanding they need from family and friends, educators and employers. In addition,

reasonable accommodation for sufferers of migraine is not always made by educational institutions and in the workplace that would enable migraineurs to perform at their very best.

There is a spectrum of migraine experiences, with people on one end of the spectrum able to function well in their everyday life with little or no burdens (other than an intermittent migraine attack) and those on their other end of the spectrum whose life is crippled by near daily migraine attacks that are not well controlled [7–9]. The \pm 20% of people who have severe migraine are most impacted by societal prejudices about the condition. These people carry most of the burdens and are impacted most by the lack of empathy for and understanding about what it is to live with severe migraine without any support from institutions, policy-makers, employers and primary care services.

The scientific community and neurologists refer to the more severe versions of migraine as chronic or refractory migraine, but these terms may not be well understood by the public or policy-makers [11].

The EMHA wants to gather information on this topic and wants to change the wrong perception that seems to exist about migraine. In this context, it is going to devote 2023 to carrying out a number of surveys and publishing papers and documents that could provide evidence to drive some of the changes that are needed. This is the message that the EMHA communicated to the scientific community at the European Headache Federation Congress in Vienna in December 2022, namely, to change the language we use when talking about migraine and communicate that there is a spectrum of experiences ranging from mild to severe [12]. Mild, moderate and severe are easier terms for people to understand. Using the term severe migraine may help focus the attention of non-specialist doctors, policy-makers and employers on the addressing the needs of the people with the more severe version of migraine and counteract perceptions that migraine is just a headache. Changing perceptions about migraine may also enable migraineurs to talk more openly about it which could have the knock-on effect of further increasing awareness about the nature of this poorly understood and

underserved condition. The broad community of people with an interest in migraine need to work together to change the language we use about the condition and be consistent in the call for action for those who are most impacted by migraine [13].

The results of this Stigma Awareness Project will be launched at the European Headache Congress in Valencia, November 2023.

THE MIGRAINE CLINICIAN EXPERT PERSPECTIVE (PAOLO MARTELLETTI)

Reversal of Migraine Stigma

I quote here the words of the WHO Director-General's Dr Tedros Adhanom Ghebreyesus from a few days ago, stated during the opening remarks at the Mental Health at Work Panel, World Economic Forum—18 January 2023: *"Yet investment in mental health remains low, and the stigma surrounding it remains high on average, countries spend around 2% of their health budget on mental health, and in some countries there are as few as two mental health workers, for every 100,000 people. And yet, mental health conditions are among the leading contributors to the global burden of disease"* [14].

In the large global picture of barriers and unmet needs, this statement seems to fit headache because of its burden, the dedicated health budget and the stigma of chronic pain conditions, as a paradigm par excellence [15].

Focusing on the theme of this kaleidoscopic overview of how each of the actors in the headache drama see or experience the stigma, as a (virtual) representative of headache physicians, I can say that we should ask ourselves whether our attitude towards the stigma experienced by the migraine patient is sufficiently comprehensive in terms of being over and above the prescribing of medication that is needed to break down this barrier that creates isolationism around the patient.

What is the right attitude of the medical expert? Is he/she being attentive to more than just than clinical data collection? Is he/she

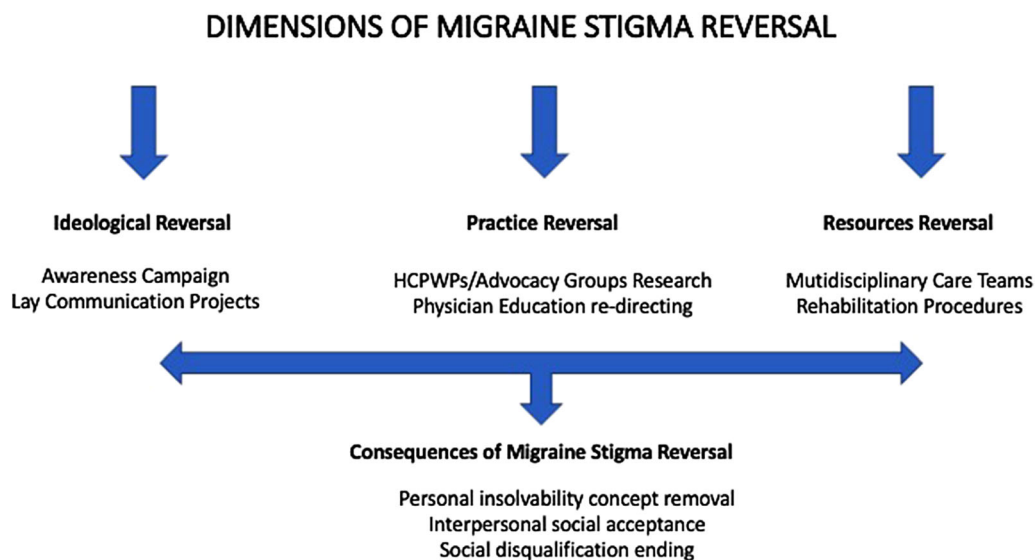


Fig. 1 Reversal of stigma. *HCPWPs*: Health Care Professional Working Groups

sufficiently attentive to the biopsychosocial reading of the context, or is only alert to the mere pharmacological response? Is he/she amendable to the search for combined solutions or does he/she only rely on the hope of the latest drug? The answer, although articulate and difficult, often does not appear to be satisfactory in the eyes of the patient.

The stigma of migraine, in addition to having public, structural and internalized components, is also affected by the gender gap. In fact, the impact of stigma on the personal well-being of individuals with migraine disproportionately affects women, and not only because the prevalence of migraine is higher in women. Sex-hormone production, societal norms and apparently less healthcare consideration also affect stigma in women [15].

Intervention strategies to reduce migraine stigma can be conceptually understood as intrapersonal, interpersonal and structural. At all three levels, the impact on productive and working activity takes on an important share of alertness in today's world [16–19].

The first strategies toward improvement are based on a renewal of the doctor-patient relationship, which requires a greater consideration of the illness on the part of the physician as well as abdication of the reverse stigma profile of the expert, defined as an incentive factor for

discontinuity in the event of expectations not being fully met. This need emerges strongly from the patient's testimony reported in the first section of this article. The second is strongly pursued by the relentless activity of patient associations, culminating at a session of the European Migraine and Headache Alliance "Are Migraine Patients Stigmatised? Do We Need Stigmatisation? Working Together to Change the Stigma on Migraine" held during the 16th Congress of the European Headache Federation [12] and which can be reviewed online [13]. This third and last part is deeply rooted on the unmet educational medical need and on the scarce availability of headache expert [20].

CONCLUSIONS

This report summarizes the kaleidoscopic views of stigma in migraine from patients' real-life experiences, the activities needed to counteract stigma by patients' associations and the skills of medical experts, who should also include the migraine stigma in their research plans and education projects for new generations of experts.

An overview is given in Fig. 1.

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Compliance with Ethics Guidelines. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

Data Availability. Data sharing is not applicable to this article as no data sets were generated or analyzed during the current study.

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