

# Brains Under Siege

## Assessing the Harmful Effects of Migraine-Related Stigma

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Biomedical research fuels progress in headache medicine. However, there are gains to be had in recognizing that migraine, like all diseases, is as much a social phenomenon as it is a biological process. Migraine, a disease that is often trivialized, interferes with every aspect of patients' lives, including their ability to work, enjoy friends and care for their families, and exercise and maintain overall health.<sup>1</sup> Less well understood is the effect that migraine-related stigma has on patient lives. Although we know migraine attracts more stigmatizing stereotypes and judgments in the news media than almost any other chronic physical health disease, limited research has how stigma affects the experience, attitudes, and health outcomes of those with migraine.<sup>2,3</sup>

This issue of *Neurology*® presents a landmark study by Shapiro et al.<sup>4</sup> providing the first population-based estimate of perceived migraine-related stigma and its relationship to health outcomes. Data came from the OVERCOME survey, a multicohort longitudinal study with a representative sample of US adults with active migraine (n = 59,001). The authors introduce a validated Migraine-Related Stigma Scale to quantify perceived stigma. This 12-item scale evaluates “Secondary Gain”—the belief that others view migraine as an excuse by malingerers—and “Minimizing Burden”—a sense that others trivialize the burden of migraine. Established research scales measured migraine-related disability, interictal burden, and quality of life.

Nearly one-third of people (31.7%) with migraine reported that they frequently (often or very often) feel subject to at least 1 form of stigma. A similar proportion (29.1%) frequently experience “Minimizing Burden.” One in 7 (14.8%) experience “Secondary Gain” stigma. Prevalence rates of migraine-related stigma increased with migraine severity; those with 8–14 or ≥15 monthly headache days were far more likely to report at least 1 form of stigma than those with <4 monthly headache days (41.2% and 47.5% vs 25.5%).

The study shows a strong link between migraine-related stigma and poor health outcomes after controlling for sociodemographics, clinical characteristics, and—intriguingly—monthly headache days. High scores on the migraine-related stigma scale (often/very often) were highly correlated with moderate-to-severe disability (75%) and moderate-to-severe interictal burden (79.7%) than those who never experienced stigma (18.6% and 11.2%). Likewise, those who experienced the highest rates of migraine-related stigma scored far lower in their migraine-related quality of life measures, with average scores of 34.8 vs 68.7 in the non-stigmatized group.

Disentangling the causal relationship between migraine-related stigma and health outcomes requires more research. However, the relationship is likely bidirectional. Stigma disproportionately targets those who miss work or family commitments due to illnesses associated with negative moral characteristics. Thus, as migraine disability increases, so does the potential for experiencing such stigma. Likewise, those experiencing more migraine-related disability may be more prone to internalizing stigma because the diagnosis becomes a larger part of their self-identity. Migraine-related stigma could also be a social determinant of health, limiting opportunities and resources, altering psychological pain responses, and diminishing medical system trust.<sup>5</sup> Stigma is a strong candidate for research for those interested in the possibility that adverse social environments play a role in the pathogenesis of migraine and chronic migraine.

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Documenting the high prevalence stigma of migraine offers vindication to many of us in the headache community. However, the findings also raise concerns about the efficacy of advocacy efforts. Headache medicine has often depicted migraines as a neurobiological disease in efforts to reduce stigma, mirroring advocacy efforts in mental health teaching the public that mental illness was a “disease like any other.”<sup>6,7</sup> Unfortunately, research has not found evidence that “medicalized frames” are effective mechanisms for stigma reduction.<sup>2,6,7</sup> Headache medicine may want to reconsider this approach, given how difficult it has been to reduce stigma in this field.

The development of a migraine-related stigma scale is a key advancement for researchers. Those adopting this scale, however, should note its limitations. Stigma is a complex social process that occurs on multiple levels: the individual level of cognition and behavior; the interpersonal level of discrimination, microaggression, and dehumanization; and the structural level of cultural norms, media messaging, and institutional policies that systematically marginalize certain groups, limiting their access to resources, health care, and opportunities for social advancement.<sup>8</sup> As the authors explain, the migraine-related stigma scale captures how people perceive migraine stigma as attitudes, words, and actions. However, it does not account for “internalized stigma,” which can present as self-blame or guilt. The scale is, therefore, best used as a measure of “perceived stigma,” rather than a general measure of “stigma.”

The patient with migraine who seeks help from a doctor carries an entire lifetime of experience, much of which will include disparaging public messages and personal insults

about their disease. As Sir William Osler once said, “The good physician treats the disease, the great physician treats the patient who has the disease.” Migraine demands the greatness that Osler hoped to inspire. The doctor who fails to understand their patients’ lifeworld may miss half the picture.

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