

## Presence of Stigma in the Treatment of Patients With Migraine Among Neurologists

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To the Editor,

Stigma is a construct in the social sciences, which describes a trait, characteristic, or diagnosis that discredits individuals and elicits prejudice, discrimination, and loss of status [1]. It attaches to diseases in many different ways. It can be “enacted” when individuals experience discrimination [1]. It can also be “internalized” or perceived which is how individuals feel about their condition and anticipation about how other may react to it [1].

A variety of different neurologic diseases including epilepsy, multiple sclerosis, and Parkinson’s disease have been shown to be stigmatizing which leads to decreased quality of life and disruption of social relationships [2–4]. This has also been studied in patients with migraine who have agreed with feeling stigmatized by their condition [1, 5, 6].

Migraine is the third most prevalent illness in the world, with roughly 12% of the US population suffering from the condition. Thus, a large subset of the population is potentially affected due to stigma toward patients with migraine. There is a shortage of migraine providers in the United States. Few medical school curricula include headache medicine and limited numbers of non-neurology residency programs have specialized training [7]. Often for neurology residents as well, the amount of training in migraine is inadequate. This lack of understanding and education is contributory to stigma against patients with migraine [7].

Studies have shown stigma against patients suffering from migraine, but no studies currently exist looking at neurology provider viewpoints toward patients with migraine. This study aimed to understand whether stigma

exists among non-headache certified neurologists, as well as understand other perceptions of patients who may have treatment implications.

A 10-question survey was created and administered to non-headache neurologists at an academic center (appendix one). Inclusion criteria were subjects who are board certified neurologists who are involved in clinical care. Exclusion criteria were neurologists who were headache board certified. A total of 33 surveys were completed out of 37. This study was approved by the hospital’s institutional review board.

A total of 67.3% of neurologists within our academic medical center responded to the survey, with half reporting that they believe there is a stigma against patients with migraine among healthcare professionals. Almost 94% of respondents did not think patients with migraine exaggerate pain, and almost 88% of respondents did not think that patients with migraine use their headaches as an excuse to avoid work. Sixty percent of respondents feel patients with migraine have a higher incidence of mental health disorders.

Almost 82% of respondents reported that they view treating patients with migraine is challenging, whereas 67% of respondents reported that they feel patients with migraine drain them emotionally. Approximately half (51.5%) of respondents had experienced a migraine themselves.

Stigma is a construct that has the potential to significantly impact patient care. Patients have reported that stigma can make receiving care difficult and creates a barrier between the healthcare provider and themselves. While there have been studies done on patients with

migraine and the stigma they perceive, no studies have been done to assess for provider perception of stigma.

Stigma against patients with migraine can be viewed differently by providers and patients. For providers, the stigma can be that the patient is viewed as difficult and as a result, depersonalization may occur. This also can contribute to increased provider burnout if they feel that these visits are more challenging and exhausting compared to those of other diagnoses [7]. For patients, stigma means that there can be difficulties in obtaining care. This can come as a result from difficulties with obtaining Family and Medical Leave (FMLA) paperwork or disability due to lack of understanding by providers about their diagnosis and their functional limitations [7]. Additionally, this can lead to an increasing anxiety and depression.

This study shows that at one academic institution, the majority of providers feel that there is a stigma towards patients with migraine. Providers did endorse that many of them found it challenging to treat patients with migraine, with roughly 82% of respondents answering affirmatively to that question. Two-thirds of the respondents felt that patients with migraine drain them emotionally. However, the overwhelming majority did not feel that patients with migraine exaggerated their pain nor did they use the migraines as an excuse to miss work.

These data show that there is a challenge that providers identify and treating patients with migraine. These data are important because it can be used to further target areas of intervention for breaking down these barriers between clinicians and patients and helping results in improved care. While providers in this study did identify that they had felt that treating these patients could be draining emotionally, they did not feel that these patients were exaggerating their symptoms or taking advantage of the medical system.

Patients have previously reported that they felt “dismissed” by physicians who did not take their pain seriously; in a focus group, patients reported that they had been told to “live with it” by a physician [8]. Half of the provider surveyed had suffered from migraines at one point in their lives themselves. This fact may have led to increased recognition of the stigma which exists in patients with migraine as those providers have likely suffered from it in the past.

Identification of stigma is amongst the first steps in breaking down this invisible barrier. Further studies into larger groups of providers is necessary to expand their absence and obtain a larger sample size. With these and future data, it will become important to create programs to break down stigma and lead to improved clinical care. Destigmatization needs to happen at the level of both patients as well as healthcare providers. At the patient level, this can be done with advocacy activities and involvement of families and friends to break down barriers [9]. At the provider level, demonstrating listening and empathizing with the patients can form a collaborative

relationship which is an instrumental portion of the patient-provider relationship.

Potential solutions to stigma include an increase in the number of headache specialists. Headache providers who undergo fellowship training are trained in the specific nuances of treating headache patients and have access to an increased volume of patient experiences. This allows for further understanding of the difficulties the patients with migraine face and allows for a more nuanced understanding of the disability and FMLA in this disease. Concurrently, increased migraine education of primary care doctors, neurology residents, and fellows, and other healthcare providers who directly deal with this group of patients is critical to increase understanding. The lessons learned in headache training can be widely disseminated, and although these providers may not have the same toolbox as those with specialized training, they can contribute and help fill the gaps of the lack of access to specialized providers.

Limitations of the study include the small sample size and a focus on providers in one department with a headache department. Additionally, the survey did not utilize a Likert scale, which may have captured a more accurate range in response to the questions. Future studies can consider looking into not only providers in the neurology department but other providers, which serve as a first line for patients with migraine including internal medicine, family medicine, and emergency medicine providers. Additionally, the specialized headache care available at the surveyed institution may limit generalizability.

Neurologists believe that stigma is common among patients with migraine. An overwhelming majority of respondents were understanding of the role that headache has in people’s lives. Neurologists feel that treating migraine could be challenging; it is important to understand these perceptions to better promote patient engagement, combat stigma, and understand how to promote resiliency within patients with migraine.

Sincerely,

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## Appendix

### Presence of stigma in treatment of migraine patients among neurologists

#### Question Title

1. How many migraine patients do you see per month??

- 1-5
- 5-10
- 10-20
- 20+

#### Question Title

2. What percentage of migraine patients do you refer to a headache specialist?

- 0-15%
- 15-30%
- 30-50%
- 50-75%
- 75%+

#### Question Title

3. Do you think that patients with migraine exaggerate their pain?

- Yes
- No

#### Question Title

4. Do you think that patients use migraine as an excuse to avoid work?

- Yes
- No

#### Question Title

5. Do you feel that migraine patients have a higher incidence of mental health issues??

- Yes
- No

#### Question Title

6. Do you feel that treating migraine patients is challenging?

- Yes
- No

#### Question Title

7. Do you feel migraine patients drain you emotionally?

- Always
- Usually
- Sometimes
- Rarely
- Never

#### Question Title

8. Do you feel there is a stigma towards migraine patients among healthcare professionals?

- Yes
- No

#### Question Title

9. Have you ever had a migraine?

- Yes
- No

#### Question Title

10. How many migraine preventive treatments do you try before referring the patient to a headache specialist?

- 1
- 2
- 3
- 4
- 5+