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Stigmatizing attitudes toward people with migraine by people without active migraine: results of the OVERCOME (US) study

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Abstract

Background Migraine is associated with various types of stigma. This study aims to evaluate stigmatizing attitudes towards people with migraine by people without active migraine.

Methods OVERCOME (US) was a web survey among adults from a representative US population-based sample that collected information about stigmatizing attitudes of people without active migraine (i.e., no migraine/severe headaches in the previous 12 months) toward people with migraine and related conditions. The following associations were examined in the current analysis: (1) association between stigma toward migraine and relationship to people with migraine, (2) association between stigma toward migraine and sex, and (3) association between stigma toward migraine and historical headache/migraine status. We further compared stigmatizing attitudes toward people with migraine compared to people with chronic low back pain and epilepsy.

Results In this observational, population-based study, a total of 11,997 respondents without active migraine were queried about attitudes and beliefs about people with migraine. With a mean age of 47.4 (standard deviation 17.3) years, the majority of the respondents were female (51.1%), White (75.6%), and non-Hispanic (82.3%). Nearly 70% of people queried endorsed ≥ 1 stigmatizing attitude from eleven possibilities. Stigmatizing attitudes and beliefs were more prevalent among those with a closer relationship to someone with migraine (family or friend) or those who knew multiple people with migraine, in particular among those who felt personally impacted by knowing a family member or co-worker/supervisor/employee with migraine or severe headache. Respondents with prior migraine endorsed more stigmatizing attitudes than those without migraine/headache history. Lastly, the analysis showed that stigmatizing attitudes toward people with migraine were much more prevalent than those toward people with epilepsy and similar to those toward people with chronic low back pain.

Conclusions Stigma towards people with migraine is widespread but surprisingly more common the closer the relationship(s) to a person/persons with migraine and in those who have experienced migraine themselves. Raising awareness about the stigma towards people with migraine that exists in public may help people with migraine feel

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more confident to advocate for themselves and seek care, as well as creating more public and social support for accommodations, research funding, and treatment.

Keywords Migraine, Stigmatizing attitudes, Survey

Background

Migraine is a potentially debilitating neurological condition that affects approximately 15% of individuals in the United States (US) annually and 1 billion globally [1–3]. Migraine attacks are often unpredictable, causing moderate to severe pain alongside other potential disabling symptoms such as nausea, sensitivity or intolerability to light, sounds and odors, and cognitive impairment. The emotional and psychological impacts and symptomology may result in significant disruption of daily activities both during and between attacks. People with migraine may face numerous challenges, such as missed or impaired school or work, family, social and leisure activities and responsibilities [4, 5], acute medication overuse [6, 7], lower health-related quality of life [8], and increased healthcare utilization and costs [9, 10].

Stigma is a social, multi-step process where classes of individuals may be subject to stereotyping, prejudice, and discrimination based upon a unifying characteristic or trait, which in this case is having migraine [11, 12]. Public or external stigma refers to negative attitudes and stereotypes held by the general public, whereas internal stigma occurs when individuals are aware of, feel, think or believe the negative stereotypes and assumptions made about people with their condition and may experience negative thoughts and emotions as a result [13]. Both types of stigma can negatively affect social relationships, relationships with healthcare professionals, and interactions in the workplace [14, 15]. In the case of public or external stigma, people may distance themselves from and/or discriminate against stigmatized individuals [11].

External perceived migraine-related stigma may add to the burden of living with migraine. It can impact multiple dimensions of life and may impede access to medical care [14, 16]. People with migraine may feel dismissed by family members, society, and healthcare professionals who can convey the sense that their condition is insignificant; [17] the resulting psychosocial stress may also negatively impact a person's health outcomes [12, 14, 16]. Public stigma is common across the spectrum of neurological and/or chronic conditions, but may be more frequent toward people with migraine and other pain disorders given the invisible nature of those conditions [12]. Surveys have been conducted to better understand these stigmatizing attitudes toward migraine. One recent study reported that half of the neurologists in an academic medical center believe that there is stigma towards people with migraine among healthcare professionals [18]. Another study showed that people with chronic migraine reported experiencing higher levels of stigma compared to those with episodic migraine and people with epilepsy [12]. Few studies have directly measured public stigma or evaluated the factors that drive these attitudes [11, 19].

The ObserVational survey of the Epidemiology, tReatment and Care Of MigrainE (OVERCOME) (US) study is a population-based web survey that evaluated migraine characteristics, treatment and outcomes in over 60,000 people with active migraine and ~ 20,000 people without active migraine ("non-migraine cohort") who were queried from 2018 to 2020 about their stigmatizing attitudes and beliefs toward people with migraine and other neurological and/or pain conditions. The current study focuses on the non-migraine cohort of OVERCOME (US) with the aim of assessing rates and types of stigmatizing attitudes toward people with migraine by people who currently do not have active migraine in a large population and compare rates with stigma towards other chronic conditions (epilepsy and chronic low back pain [CLBP]) to put this stigma into context.

Methods

As previously described [20], a sampling frame from the general population (large on-line consumer panels) was screened for migraine using a diagnostic questionnaire [21] based on the criteria from the third edition of the International Classification of Headache Disorders (ICHD-3) [22] or a self-reported diagnosis of migraine from a healthcare provider. Respondents who did not screen positive for migraine were invited to be part of the non-migraine cohort. Respondents were eligible for the non-migraine cohort if they historically (1) never had migraine/severe headaches, (2) had prior non-migraine headaches that did not occur in the previous 12 months (i.e., did not have active migraine at the time the survey was conducted), or (3) had prior migraine that did not occur in the previous 12 months (i.e., did not have active migraine at the time the survey was conducted). Eligible participants were aged ≥ 18 years, residents of the United States, members of the online survey panel, able to read and write English, had access to the internet, and provided electronic informed consent. This observational study was approved by the Sterling Institutional Review Board (IRB ID #6425-001).

This population without current active migraine (hereafter named non-migraine cohort) was surveyed to understand their perceptions of people with migraine. The survey was approximately 10 minutes in length and contained questions about demographics (including sex at birth), lifestyle, comorbidities/health status, healthcare resource utilization, quality of life, disability/burden/impact, and attitudes/perceptions towards and beliefs about people with migraine ('stigma'). Eleven attitudinal questions were developed from qualitative research with migraine patient focus groups and separately with migraine healthcare professional and scientist experts. Questions had the stem "how often have you felt that people with migraine…" followed by each of the 11 attitudinal statements (listed in Fig. 1). Response options were a 5-point Likert scale with the options 'never', 'rarely', or 'don't know' (categorized as 'no') and 'sometimes', 'often', or 'very often' (categorized as 'yes').

The following associations were examined in the current analysis: (1) association between stigma and relationship to people with migraine by proximity of relationships, (2) association between stigma and sex at birth, and (3) association between stigma and historical headache/migraine status. To understand a person's relationship to someone with migraine, respondents answered the question "Do you have family, friends, or co-workers who have migraine" by selecting all that apply from a list of answers which included the following: (1) family in my household (spouse, children, step-child, parent), (2) family I no longer live with (children who have moved out, siblings living in the same household, ex-spouse), (3) extended family, in-laws (aunt, mother-in-law, cousin, etc.), (4) close friend, (5) casual friends, neighbors, teammates, club members, or others you know casually, and (6) co-workers, supervisor, or employees. The provided answers were then combined into a 4-category variable: family/friend(s) only, co-worker(s) only, multiple people, or none. A sub-analysis was conducted among respondents who stated they knew a family member or a co-worker with migraine; respondents were then asked a further series of questions to assess the extent of any personal impact by their family member's/co-worker's condition.

To assess respondents' headache/migraine history, respondents were asked whether they 'ever had headaches that were not caused by hangovers or illness', and whether they 'think that those headaches were migraine'. No information on frequency of potential historical headaches was collected in the survey. Depending on their answer, respondents were grouped into one of the following groups: (1) historical headaches – no, (2) historical headaches – yes, thought they were migraine – no, or (3) historical headaches – yes, thought they were migraine – yes. Respondents were also queried about their tobacco and marijuana use as well as comorbidities and health status, including mental health using the Patient Health Questionnaire for Depression and Anxiety (PHQ-4) [23].

In addition to participants queried about attitudes toward migraine ($n = 11{,}997$), OVERCOME (US) also included small cohorts of respondents queried about attitudes toward other neurological conditions, including chronic low back pain (CLBP, $n = 2{,}000$) and epilepsy ($n = 1{,}999$). These cohorts were included in this assessment for context and comparison of attitudes toward other conditions with some similar qualities (e.g., pain, disability). Supplemental Fig. 1 shows participant flow and disposition of the population sampled for attitudes toward certain conditions. Of note, comorbidities were also assessed as part of the questionnaire and if a participant answered 'yes' to having epilepsy or CLBP, they were excluded from answering survey questions about attitudes towards people with epilepsy or CLBP, respectively.

Data were described by frequencies (%) or means (standard deviation). Standardized mean differences (SMD) were calculated for comparisons between groups; values < 0.2 indicated no difference, 0.2–0.49 a small

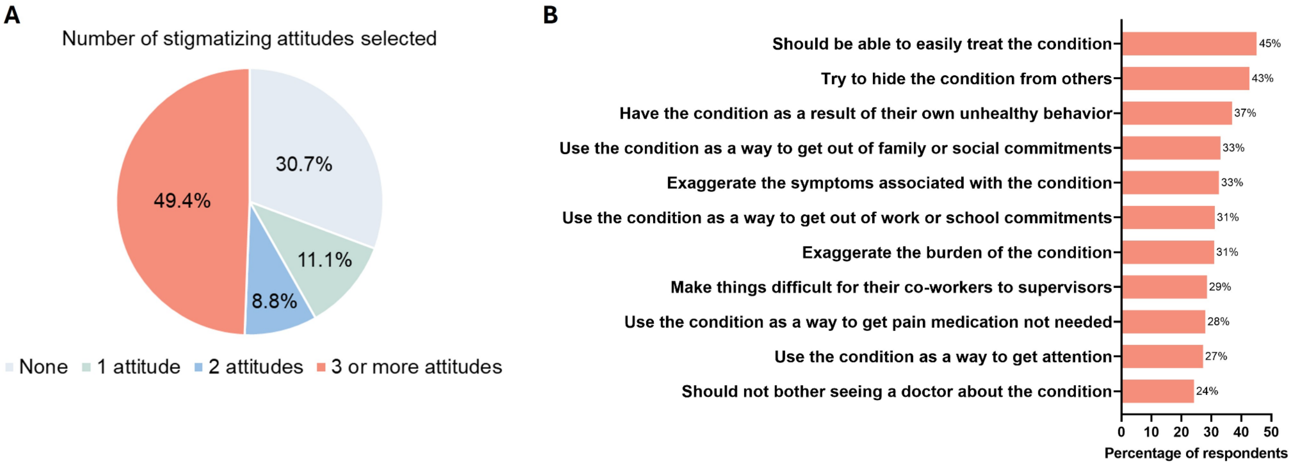

Fig. 1 Number of stigmatizing attitudes and beliefs endorsed by respondents (**A**) and stigmatizing attitudes and beliefs toward people with migraine by frequency (**B**). Non-migraine cohort surveyed about stigmatizing attitudes toward people with migraine, $N = 11{,}997$

Table 1 Demographic characteristics – respondents queried about migraine

	Respondents queried about migraine or severe headache *N* = 11,997
Age, mean (SD)	47.4 (17.3)
Sex, n (%)	
Female	6,126 (51.1)
Male	5,871 (48.9)
Race, n (%)	
White	9,069 (75.6)
Black or African American	1,542 (12.9)
Asian or Asian American	714 (6.0)
Other/prefer not to answer	672 (5.6)
Ethnicity, n (%)	
Not Hispanic or Latino/a	9,872 (82.3)
Hispanic or Latino/a	1,785 (14.9)
Prefer not to answer	340 (2.8)
Region, n (%)	
Northeast	2,106 (17.6)
Midwest	2,646 (22.1)
South	4,694 (39.1)
West	2,551 (21.3)
Rural/Urban Commuting Area (RUCA), n (%)	
Urban	10,039 (83.7)
Rural	1,614 (13.5)
Prefer not to answer	344 (2.9)
Children under age 18 living in household, n (%)	3,478 (29.0)
Married/living with partner, n (%)	6,020 (50.2)
Household income, n (%)	
≤$49,999	5,778 (48.2)
$50,000 – $99,999	3,516 (29.3)
≥$100,000	2,309 (19.2)
Prefer not to answer	394 (3.3)
Education, n (%)	
High school or less	2,996 (25.0)
Some college	4,031 (33.6)
College degree	4,885 (40.7)
Prefer not to answer	85 (0.7)
Employment status, n (%)	
Full time	4,674 (39.0)
Part time	1,491 (12.4)
Homemaker	714 (6.0)
Retired	2,601 (21.7)
Other	2,517 (21.0)
Relationship to person with migraine, n (%)	
None	5,296 (44.1)
Co-worker only	505 (4.2)
Family or friend only	5,419 (45.2)
Know multiple people	777 (6.5)

SD, standard deviation

difference, 0.5–0.79 a moderate difference, and ≥0.8 a large difference.

Results

Stigmatizing attitudes towards people with migraine

A total of 11,997 respondents without active migraine were queried about their attitudes toward and beliefs about people with migraine (Supplemental Fig. 1). Respondents' mean age was 47.4 (standard deviation [SD] 17.3) years and 51.1% were female (Table 1). The majority of respondents were White (75.6%) and non-Hispanic (82.3%). About half (50.2%) of respondents were married or living with a partner, 40.7% were college graduates, and 48.5% reported a household income ≥$50,000.

A total of 69.3% of respondents queried about their attitudes toward and beliefs about people with migraine answered 'yes' to ≥ 1 of the attitudinal questions; 49.4% of respondents selected 3 or more 'yes' responses (Fig. 1A). The most frequent responses included the belief that people with migraine should be able to easily treat their condition (45.1%), that people with migraine try to hide their migraine from others (42.7%), and that people have migraine as a result of their own unhealthy behavior (36.9%; Fig. 1B).

Stigmatizing attitudes towards people with migraine by relationship to someone/others with migraine

Among the population without active migraine, the relationships of respondents to a person with migraine were: knowing a family member or friend only (45.2%), knowing a co-worker with migraine only (4.2%), knowing multiple people with migraine (6.5%), and knowing nobody with migraine (44.1%; Table 1).

Stigmatizing attitudes were more commonly endorsed by respondents who knew ≥ 1 person with migraine (coworker only, family or friend only, or multiple people) compared with those who knew none (SMD ≥ 0.2; Fig. 2). The attitudes with the highest percentage of affirmatory responses among respondents who knew ≥ 1 person affected by migraine were: try to hide the condition from others (60.1%), should be able to easily treat their condition (59.5%), and have the condition as a result of their own unhealthy behavior (57.8%). Responses were lower but generally similar between respondents who knew family or friends or a co-worker with migraine. Of note, there was no difference in stigmatizing attitudes between those who were married and/or living with a partner versus those who were not (data not shown).

To understand whether the impact of knowing, working with or living with someone with migraine, the survey included questions to determine whether individuals having a family member (*n* = 4,313) or a co-worker/supervisor/employee (*n* = 3,053) with migraine or severe headache had been personally impacted by their condition.

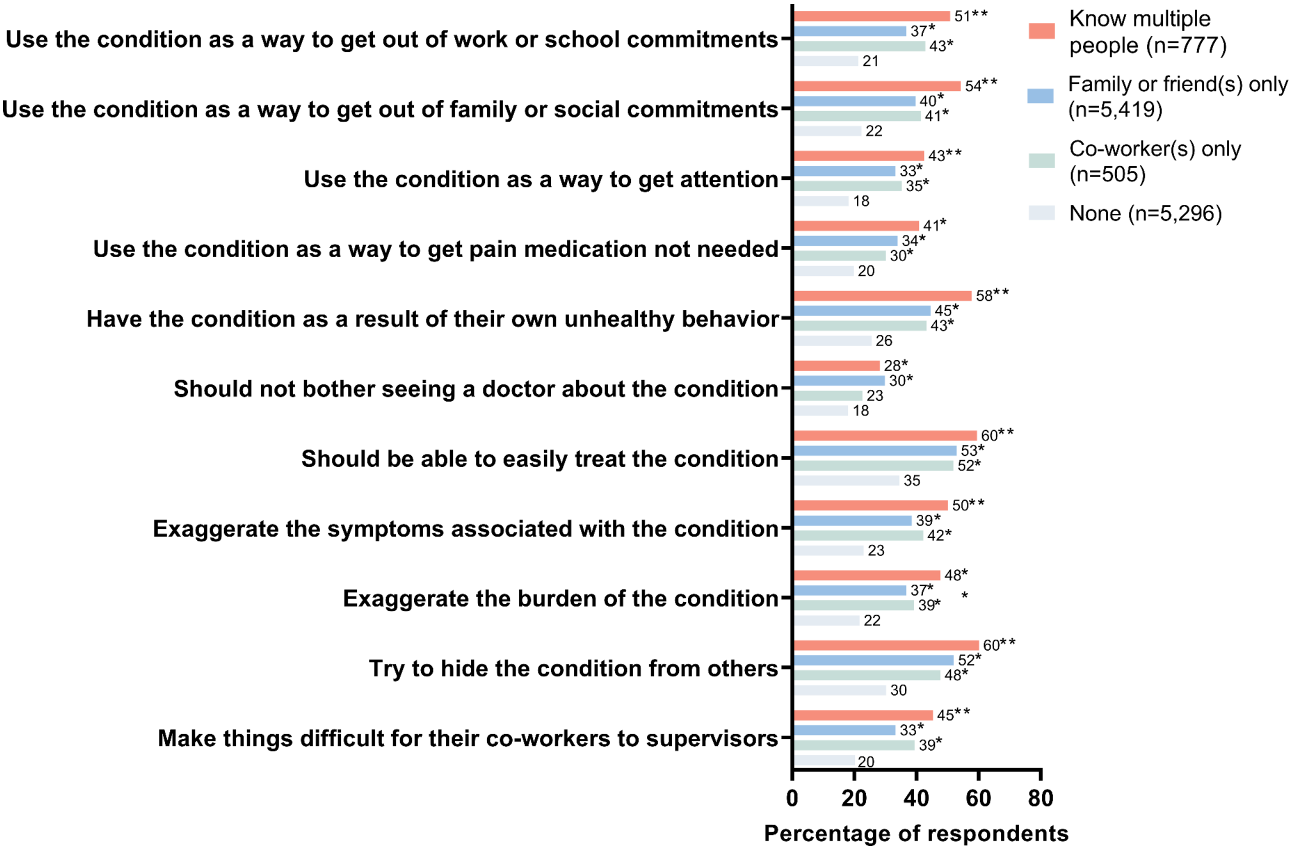

Fig. 2 Stigma towards people with migraine by relationship(s) with people with migraine. Standardized mean differences were used to determine comparisons between groups (all groups were individually compared to the group "None"). SMD values < 0.2 were considered not different, * indicates a small difference (SMD = 0.2–0.49), ** a moderate difference (SMD = 0.5–0.79), and *** a large difference (SMD ≥ 0.8)

Importantly, 15.7% of those with a family member with migraine or severe headache stated they had to take time off work to help them with their migraine/severe headache, and 9.1% reported having to ask an employer to adjust work schedules to help them with their migraine/severe headaches, indicating a large caregiver impact. A more detailed breakdown of these life implications is presented in Table 2. When we explored the stigmatizing attitudes among this group, we found that all stigmatizing attitudes were more commonly endorsed among these respondents who had been personally impacted by a family member with migraine or severe headache versus those who reported that they had not been impacted (SMD > 0.2, Fig. 3A). Specifically, 64.3% among those who had felt impacted reported that people with migraine should be able to easily treat the condition (vs. 50.6% who did not feel impacted, SMD = 0.28), 61.8% reported that people with migraine try to hide the condition from others (vs. 49.4%, SMD = 0.25), and 57.0% reported that people with migraine have the condition as a result of their own unhealthy behavior (vs. 42.1%, SMD = 0.30; Fig. 3A).

A total of 3,053 respondents indicated ever having been impacted by a co-worker/supervisor/employee with migraine or severe headache. Among this group, 19.8% reported that they had to work extra hours for them and 10.2% indicated that they had to cover their work when they lost their job (see Table 2 for more detail). Similarly, all stigmatizing attitudes were more commonly endorsed among respondents who had ever been impacted by a co-worker/supervisor/employee with migraine or severe headache versus those who reported that they had not been impacted (SMD > 0.2, Fig. 3B). In this group, 61.9% of people who felt impacted by a coworker/supervisor/employee with migraine or severe headache reported that people with migraine should be able to easily treat the condition (vs. 44.2% who did not feel impacted, SMD = 0.36), 59.3% reported that people with migraine use the condition as a way to get out of family or social commitments (vs. 30.6%, SMD = 0.60), and 59.3% reported that people with migraine have the condition as a result of their own unhealthy behavior (vs. 34.1%, SMD = 0.52) (Fig. 3B).

Table 2 Impacts on respondents who reported they knew a family member or co-worker/supervisor/employee with migraine or severe headache

	Participants who have ever been impacted by a family member with migraine or severe headache[§] **(*n* = 4,313)**
n (%)	**Yes**
Had to take time off work to help them with their migraine/severe headache	678 (15.7)
Had to ask an employer to adjust work schedule to help them with their migraine/severe headache	393 (9.1)
Not able to take a job or promotion	196 (4.5)
Had to limit education/training or change goals	202 (4.7)
Had conflicts with co-workers or supervisors	239 (5.5)
Failed a class or had to drop out	89 (2.1)
Delayed having children, limited the number of children, or not had any children	87 (2.0)
	Participants who have ever been impacted by a co-worker/supervisor/employee with migraine or severe headache[§§] **(*n* = 3,053)**
n (%)	**Yes**
Worked extra hours to cover for them	605 (19.8)
Had to cover their work when they lost their job	310 (10.2)
Had conflicts with co-workers, supervisors, or employees because of their migraine/severe headache	163 (5.3)
Had to ask an employer to adjust work schedule or position to avoid working with them	84 (2.8)
Refused a job offer or promotion to avoid dealing with someone with migraine/severe headache	56 (1.8)

[§] Participants who indicated they knew a family member with migraine or severe headache (*n* = 4,313) were asked to select all that apply from the options listed in the table in response to the question 'because of your family members' migraine or severe headache, have you ever…

[§§] All participants (*n* = 11,997) were asked to select all that apply from the options listed in the table in response to the question 'because of your co-worker's, supervisor's, or employee's migraine or severe headache, have you ever'…

Stigmatizing attitudes towards people with migraine by sex at birth

This study also aimed to understand potential differences in stigmatizing attitudes by sex at birth. Among the 11 stigmatizing attitudes evaluated, the top three attitudes endorsed by males and females were that someone with migraine should be able to easily treat their condition (males 46%, females 44%), try to hide their condition from others (males 42%, females 44%), and have the condition as a result of their own unhealthy behavior (males 39%, females 35%; Fig. 4). There was no difference (SMD < 0.2) between the proportion of males and females endorsing these attitudes.

Stigmatizing attitudes towards people with migraine by prior headache status

To understand possible differences in negative attitudes, this analysis also assessed stigmatizing attitudes by prior headache status (no prior headaches vs. prior non-migraine headaches vs. prior headaches thought to be migraine). The results showed that stigmatizing attitudes increased from respondents with no prior headaches to those with prior non-migraine headaches and were significantly more common among those reporting prior headaches they thought were migraine (SMD > 0.2 for all; Fig. 5). The attitudes among these respondents with prior headaches they thought were migraine compared to those with prior non-migraine headaches and those with no prior headaches, respectively, were that people with migraine: should be able to easily treat the condition (61.4% vs. 50.3% vs. 37.5%), try to hide the condition from others (60.4% vs. 49.8% vs. 33.2%), and have the condition as a result of their own unhealthy behavior (49.6% vs. 42.1% vs. 30.0%). Stigmatizing attitudes were least common among respondents who reported they had never had headaches.

To further characterize respondents with and without prior headache/migraine experience, we assessed comorbidities and health status reported by respondents across the entire study population without active migraine. Those with prior migraine or prior non-migraine headaches more frequently reported other comorbidities compared to those without prior headaches, including allergies/hay fever (22.6% vs. 26.0% vs. 16.6%), asthma (17.6% vs. 11.6% vs. 9.1%), and digestive issues (18.7% vs. 20.1% vs. 13.7%; Supplemental Table 1). Similarly, tobacco and marijuana use was more frequently reported by respondents with prior migraine (39.5% and 35.8%, respectively) compared to those with prior non-migraine headaches (23.6% and 19.1%, respectively) and those with no prior headaches (24.0% and 17.4%, respectively). Mean PHQ-4 score (depression and anxiety symptomology) was highest in respondents with prior migraine (8.2; SD 3.5) versus 6.8 (SD 3.1) in those with prior non-migraine headaches and 6.1 (SD 2.9) in those who never had headaches.

Stigmatizing attitudes towards people with epilepsy or people with CLBP

To place the stigmatizing attitudes toward people with migraine in context we also examined the cohorts that

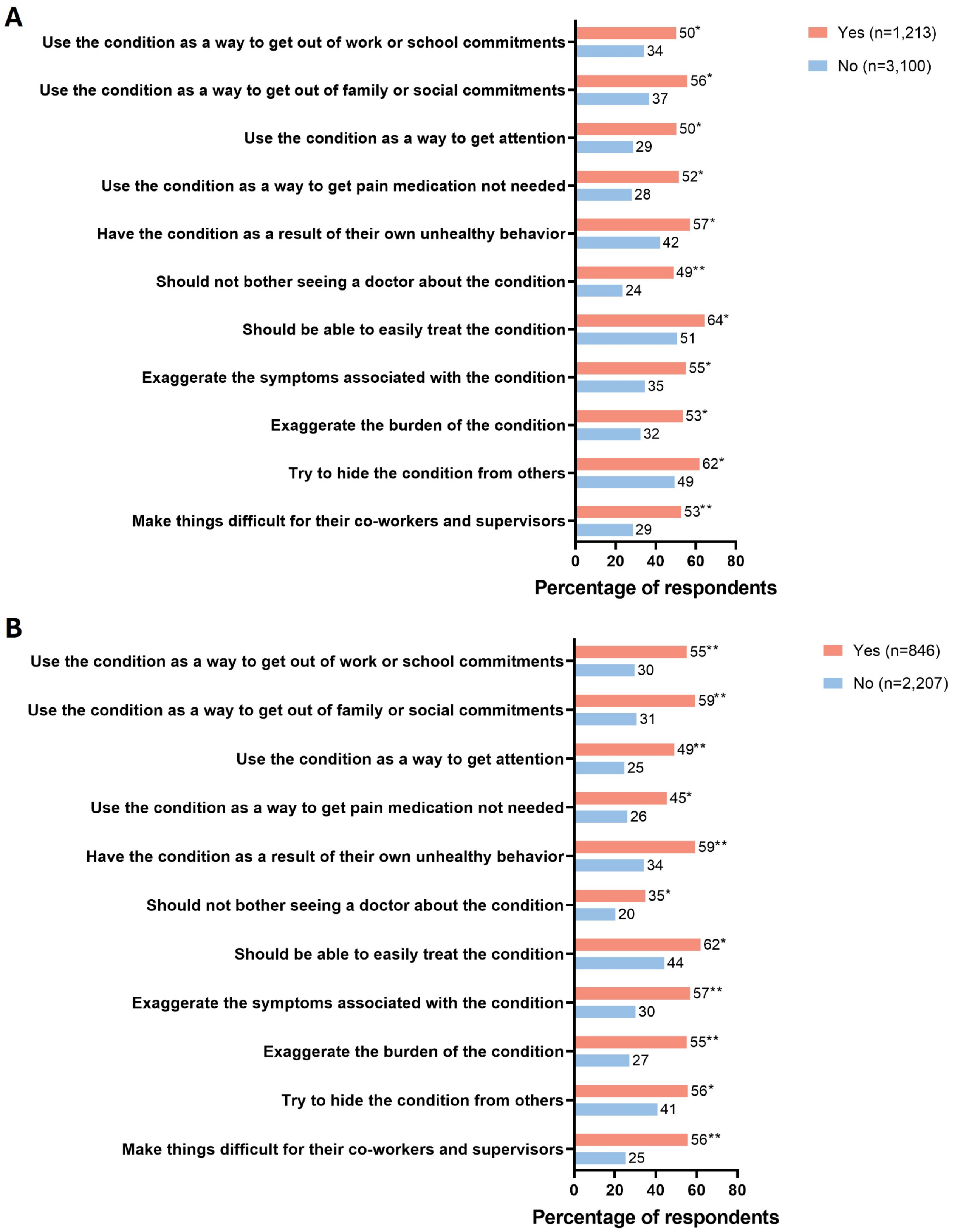

Fig. 3 (See legend on next page.)

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Fig. 3 Stigma towards people with migraine among respondents who felt impacted ("Yes") by having a family member with migraine (**A**) and a co-worker/supervisor/employee with migraine (**B**) vs. those who did not feel impacted ("No"). Standardized mean differences were used to determine comparisons between those who indicated they felt impacted by having a coworker/supervisor/employee or family member with migraine ("Yes") vs. those who did not feel impacted ("No"). SMD values < 0.2 were considered not different, * indicates a small difference (SMD = 0.2–0.49), ** a moderate difference (SMD = 0.5–0.79), and *** a large difference (SMD ≥ 0.8)

were assessed regarding their attitudes toward two other conditions: CLBP and epilepsy. A total of 2,000 respondents from the non-migraine cohort who did not have CLBP and/or epilepsy were queried about their attitudes toward people with CLBP and 1,999 were queried about attitudes toward people with epilepsy (Supplemental Table 2).

Mean age for respondents to attitudes towards people with CLBP was 46.9 (SD 16.8) years and 53.7% were female. The majority of respondents were White (76.6%) and non-Hispanic (83.1%). About half (54.9%) of respondents were married or living with a partner, 44.3% were college graduates, and 49.8% reported a household income ≥$50,000. Sociodemographics between the migraine and CLBP groups were not different (SMD < 0.2). Relationships of respondents to a person with CLBP were: family or friend only (34.6%), co-worker only (3.2%), multiple people (4.7%), and none (57.6%).

For respondents to attitudes towards people with epilepsy, mean age was 47.6 (SD 16.2) years and 52.9% were female. The majority of respondents were White (76.7%) and non-Hispanic (84.1%). About half (55.1%) of respondents were married or living with a partner, 41.2% were college graduates, and 49.5% reported a household income ≥$50,000. Sociodemographics between the migraine and CLBP groups were not different (SMD < 0.2). Relationships of respondents to a person with epilepsy were: family or friend only (22.1%), co-worker only (2.2%), multiple people (0.9%), and none (74.8%).

Proportion of respondents endorsing stigma-related attitudes for migraine, CLBP, and epilepsy are presented in Supplemental Fig. 2. This analysis showed that stigmatizing attitudes toward people with migraine are much higher than toward people with epilepsy (SMD ≥ 0.2 for all except one attitude), and similar to those toward people with CLBP (SMD < 0.2). To highlight a few, 45.1% thought that those with migraine should be able to easily treat their condition, while only 28.7% thought the same of people with epilepsy (SMD = 0.34). Further, 36.9% of those queried about their attitudes toward migraine thought that people have the condition as a result of their own unhealthy behavior, compared to 12.6% thinking the same about people with epilepsy (SMD = 0.59). Lastly, 33.0% thought that those with migraine use the condition to get out of family or social commitments, but only 12.7% thought the same of people with epilepsy (SMD = 0.50).

Discussion

To the best of our knowledge, this is the first population-based study of migraine stigma among people without active migraine in the U.S. Nearly 70% of respondents endorsed ≥ 1 stigmatizing attitude or belief. Given the prevalence of migraine, it is remarkable how few people claim or realize that they know someone with the disease (44.1% overall). These results are comparable to those from a similar survey of respondents in Europe [24]. While 55.9% of respondents know someone with migraine, their attitudes were still harsh and prevalent. A substantial percentage (23–60%) of this sample of the U.S. population holds attitudes that people with migraine malinger, are responsible for their condition, and hide it from others.

We found that the closer respondents' relationship to people with migraine the more prevalent their stigmatized attitudes and beliefs were. A similar pattern has also been observed in studies of stigma in mental illness [25]. For respondents who did not have migraine themselves but know more people with migraine, their responses may be a reaction to how the disability of those with migraine impacted them personally, i.e., there may be negative attitudes deriving from work or family responsibilities that they picked up as a result. These attitudes may also stem from a lack of knowledge, interest, or compassion in understanding and believing the impact of migraine attacks. Some respondents may have a general stigmatizing attitude but cannot point to a specific reason for it. Males were equally likely to endorse stigmatizing attitudes as females. However, our data evaluated respondents' sex at birth, not gender. Stigmatizing attitudes may differ by sex and/or gender; because migraine is more prevalent in women, it is still sometimes perceived as a "female illness" and, therefore, less legitimate [26, 27].

Stigmatizing attitudes were more common in respondents reporting a history of migraine. This may be due to lived experience that has led them to believe that migraine is not a 'big deal' and thus could lead to their having these negative attitudes. These people may experience some self-stigma and may agree that while migraine can be disabling, it is not worth making a big deal of it. These respondents may also have experienced low frequency, lower pain intensity, low symptomology and/or shorter migraine attacks and experienced less, if any, negative impact from migraine; as a result, they may not believe that migraine is a disabling condition. People with low-frequency and/or less impactful migraine who hide

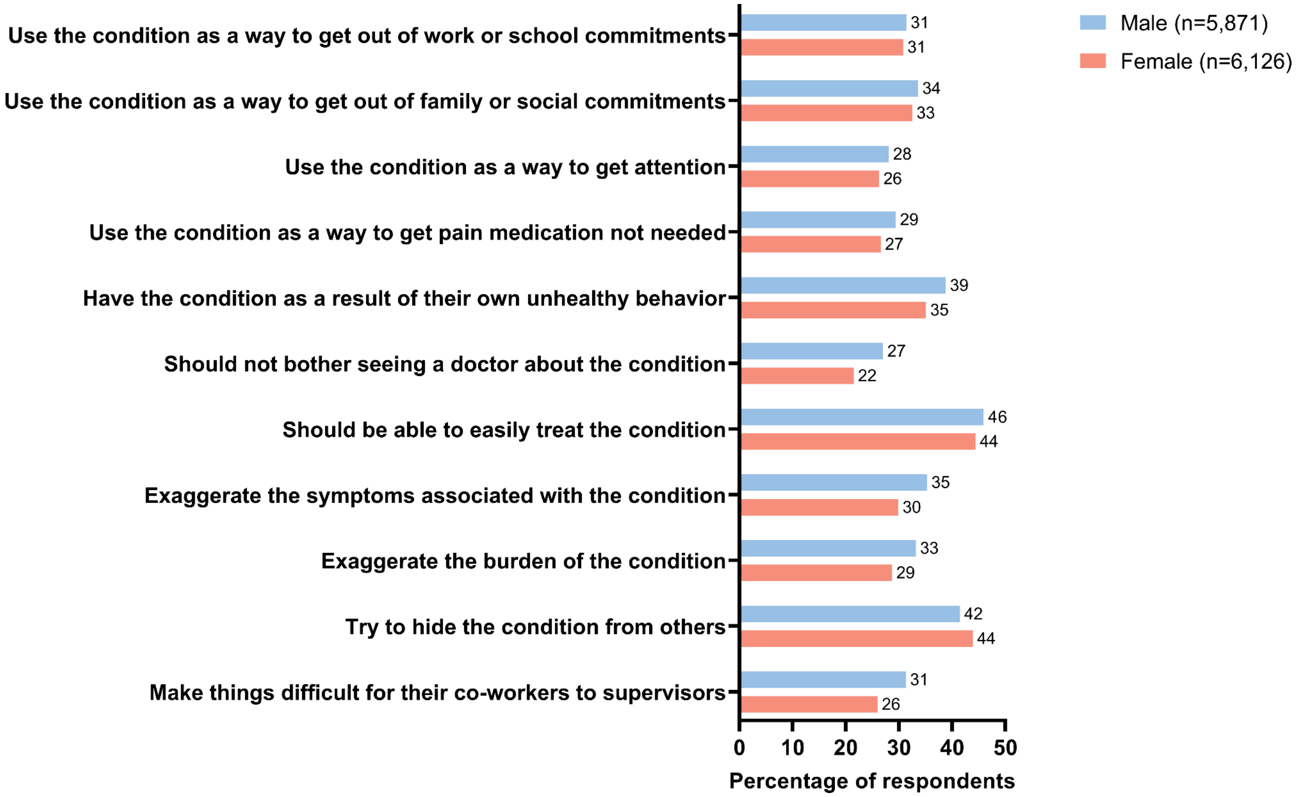

Fig. 4 Stigma towards people with migraine by sex at birth. Standardized mean differences were used to determine comparisons between males vs. females. All SMD were < 0.2 (i.e., no difference)

their condition may find that those with higher frequency and/or more impactful migraine (who do not hide this trait and claim disability) may make it harder for those with low-frequency migraine to hide their own migraine. Those with low-frequency migraine may have more resilience, more accommodations and/or other favorable variables (higher employment rates, higher income, etc.) than propensity-matched populations without migraine [28]. Therefore, they may be less tolerant of claims by others that migraine is disabling. Alternatively, people with past migraine may think that migraine is in fact disabling but endorse the stigma towards people with migraine in order to distance themselves from the stigmatized identity which they either no longer self-recognize, or they wish to abandon because the identity is a barrier to full social acceptance. This sort of self-stigma may be akin to the pathology of 'internalized oppression' [29]. More respondents with historical headache/migraine had other comorbidities, scored higher on the mean PHQ-4 showing more symptoms of depression and/or anxiety, and reported using tobacco or marijuana (which may be a means to cope with headache or migraine).

More than half (55.9%) of respondents queried about migraine knew ≥ 1 person with migraine; however, respondents queried about CLBP and epilepsy only knew few people with these conditions (42.4% and 25.2%, respectively). Nearly half (45.2%) of those queried about migraine knew a friend or family member with the conditions, whereas those queried about CLBP and epilepsy only knew very few family members or friends with these conditions (3.2% and 2.2%, respectively). Notably, the prevalence for epilepsy is lower in the US population (~ 1%), [30] while the prevalence of CLBP (~ 13%) [31] is closer to that of migraine (~ 15%) [1]. Stigmatizing attitudes towards people with migraine were largely similar to those towards CLBP, whereas these were lower towards epilepsy. A recent study by Koseahmet et al. reported significantly higher scores of internalized stigma using the Neuro-QoL Stigma Scale scale among people with epilepsy compared to those with migraine; [32] it is important to note that the survey was conducted in Turkey and migraine-related stigma can vary by nation and culture [33]. The current study evaluated stigmatizing attitudes by querying participants who did not have the condition in question. Epilepsy is a 'visible' condition (that is, seizures are visible, though epilepsy is invisible interictally), so it may be less stigmatized than 'invisible' conditions such as migraine and CLBP. These 'invisible' disorders comprise ~ 80% of disability [34], and people with invisible disorders may experience more stigma than those with visible disorders, including "distrust, suspicion, and discriminatory behaviours" [35].

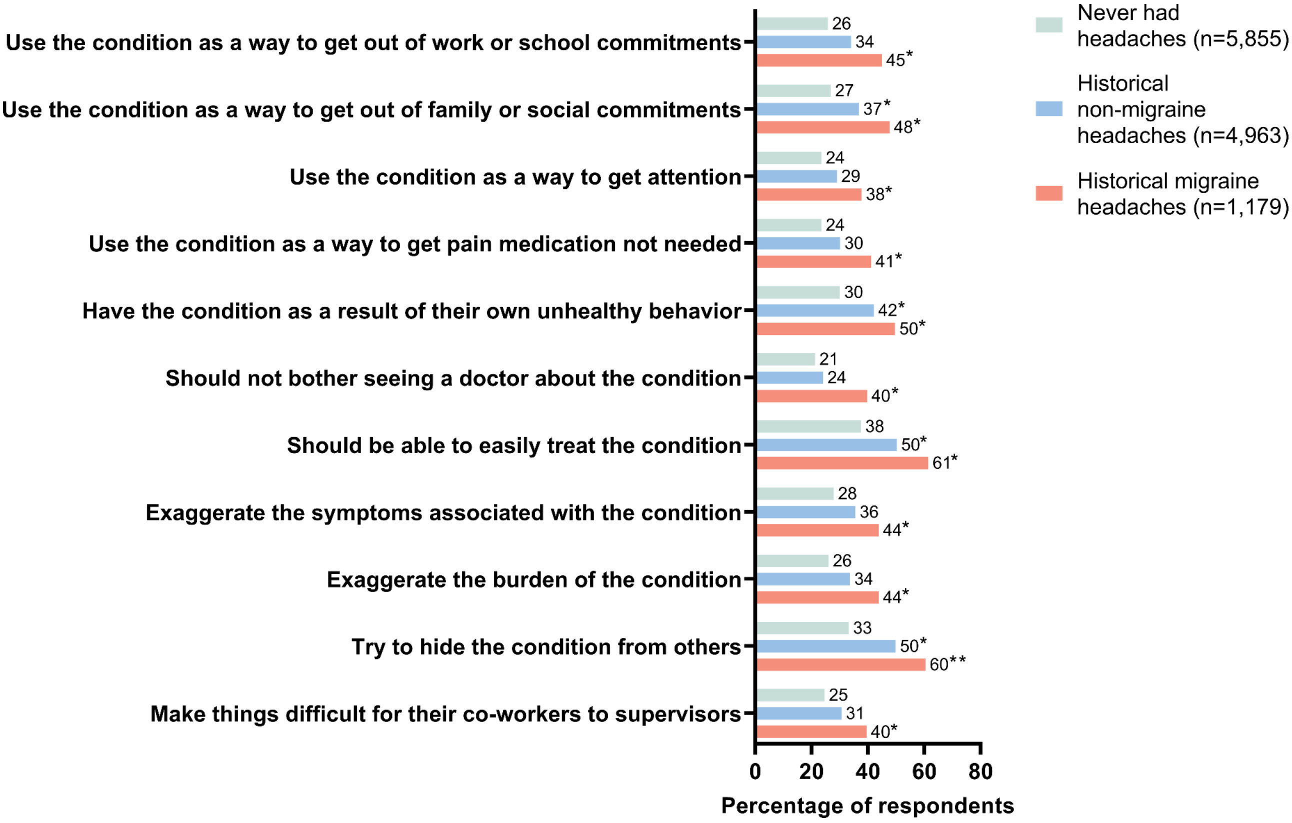

Fig. 5 Stigma towards people with migraine by prior headache status. Standardized mean differences were used to determine comparisons between those who had historical headaches (migraine or non-migraine) vs. those who did not. SMD values < 0.2 were considered not different, * indicates a small difference (SMD = 0.2–0.49), ** a moderate difference (SMD = 0.5–0.79), and *** a large difference (SMD ≥ 0.8)

Strengths and limitations

This study is strengthened by the general population-based sampling to match the U.S. Census, using a large sample size. It was conducted as novel migraine preventive therapeutics were entering the market, and is also strengthened by its novelty among recent studies of internalized stigma in the field, which have focused on querying people with migraine. However, generalizability is limited as the eligible participants were not randomly sampled. Additionally, questions on attitudes towards and beliefs about people with migraine were derived from qualitative interviews among people without migraine but further validation was not performed prior to the survey. Moreover, questions on attitudes and beliefs about people with CLBP and epilepsy were not qualitatively generated or validated specifically for these conditions and may not accurately reflect the most relevant stigmatizing attitudes toward these conditions. Finally, other attitudes may have been a factor in responses but were not captured due to the self-disclosure nature of the survey, a finite range of questions, topics, and response options.

Conclusions

People with migraine are subject to stigma by people with and without migraine and/or headache. In this study, a higher prevalence of stigmatizing attitudes was observed among respondents with closer and more frequent relationships with people who have migraine. More respondents with historical headache/migraine had other comorbidities, scored higher on the mean PHQ-4, and reported using tobacco or marijuana. Stigmatizing attitudes increased from respondents with no history of any headache to those with historical non-migraine headaches, and were more common in those reporting a history of migraine. Stigmatizing attitudes and beliefs were more prevalent towards people with migraine and CLBP, while they were less pronounced towards people with epilepsy. Our findings highlight the need to increase advocacy and awareness in order to reduce these stigmatizing attitudes towards people with migraine and as a result increase accommodations, support, and opportunities for people with migraine.

Abbreviations

CLBP	Chronic low back pain
ICHD-3	International Classification of Headache Disorders

OVERCOME	ObserVational survey of the Epidemiology, tReatment and Care Of MigrainE
PHQ-4	Patient Health Questionnaire for Depression and Anxiety
SMD	Standardized mean difference

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12883-025-04039-1.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

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Author contributions

LV, EJM, AJZ, and RAN analyzed the data; all authors interpreted the data and substantively revised, read, and approved the final manuscript.

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Data availability

Lilly will provide access to anonymized individual participant data collected during the study. The data will be available to request on vivli.org after the study team has completed analyses and publications. Access will be provided after a proposal has been approved by an independent review committee identified for this purpose and after receipt of a signed data sharing agreement. After a proposal is approved, data and documents, including the study protocol, will need to be provided in a secure data sharing environment. For details on submitting a request, see the instructions provided at www.vivli.org.

Declarations

Ethics approval and consent to participate

All participants provided electronic informed consent. This observational study was approved by the Sterling Institutional Review Board (IRB ID #6425-001).

Consent for publication

Not applicable.

Competing interests

Funding for this study was provided by Eli Lilly & Company. LV, EJM, AJZ, RAN: employees of Eli Lilly & Company. RES: consulting fees from Eli Lilly & Company, Theranica; travel or meeting support from Eli Lilly & Company; participation on monitoring or advisory board with Eli Lilly & Company; leadership or fiduciary role with Headache Cooperative of New England. DB: consulting fees from AbbVie, Biohaven, Collegium, Eli Lilly & Company, Lundbeck, Teva, Theranica; payment or honoraria from Lundbeck, Teva; participation on monitoring or advisory board with AbbVie, Eli Lilly & Company, Lundbeck, Teva. SA: consulting fees from AbbVie/Allergan, Eli Lilly & Company, Lundbeck, Theranica, Linpharma, Satsuma, Pfizer; payment or honoraria from Teva, Eli Lilly & Company, Lundbeck; leadership or fiduciary role with Educational Committee of HIS, trustee of HIS board. SH: consulting fees from AbbVie, Amgen, Biohaven, Impel, Eli Lilly & Company, Lundbeck, Theranica, Upsher Smith; payment or honoraria from AbbVie, Biohaven, Impel, Eli Lilly & Company, Lundbeck, Teva, Theranica, Upsher Smith. RBL: grants or contracts from US Food & Drug Administration, Migraine Research Foundation, National Headache Foundation; royalties or licenses from Wolff's Headache 7th and 8th Edition, Oxford Press University, 2009, Wiley and Informa; consultant, advisory board member, or received honoraria from AbbVie (Allergan), American Academy of Neurology, American Headache Society, Amgen, Avanir, Axon, Axsome, Biohaven, Biovision, Boston Scientific, Dr. Reddy's (Promius), Electrocore, Eli Lilly & Company, eNeura Therapeutics, Equinox, GlaxoSmithKline, Grifols, Lundbeck (Alder), Manistee, Merck, Pernix, Pfizer, Satsuma, Supernus, Teva, Trigemina, Vector, Vedanta; stock or stock options from Axon, Biohaven Holdings, CoolTech, Manistee.

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