The Public’s Perception of Interventions for Migraine Headache Disorders: A Crowdsourcing Population-Based Study

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Abstract

**Background:** Migraine disorders are a leading cause of morbidity and decreased economic productivity in the United States among both men and women. As such, it is important to consider patient opinions, and have an accurate representation of the burden and sentiment toward currently available interventions among those suffering from migraines.

**Objectives:** The aim of the study was to assess patient options regarding adverse outcomes of the various treatment options available for migraine headaches.

**Methods:** A prospective cross-sectional study of volunteers recruited through an internet crowdsourcing service, Amazon Mechanical Turk, was conducted. Surveys were administered to collect patient-reported opinions regarding adverse outcomes of both surgical and nonsurgical treatment options for migraine headaches.

**Results:** The prevalence of migraine headache across all study participants was 15.6% and varied slightly across participant demographics. Individuals ages 35–44 (2.73 migraines per month) experienced the fewest migraine and with the lowest severity. Those individuals ages 45+ experienced the most severe headaches (Visual Analog Scale = 44.23 mm). Additionally, the greatest migraine frequency and severity existed among those households with yearly income of $75,000–$100,000. The lowest injection therapy utility scores were obtained for adverse outcomes of hematoma (47.60 mm) and vertigo (54.40 mm).

**Conclusions:** Migraine headaches remains a significant problem among the US population, with an overall prevalence of 15.6% (approximately 50 million Americans). Additionally, physicians interesting in offering minimally invasive or surgical treatment for migraine headaches should focus on mitigating patient fears regarding clinical outcomes and cost of care.

Migraine and recurrent headaches are one of the leading causes of morbidity and decreased economic productivity in the United States. As such, it is important to have an up-to-date understanding of the burden and sentiment among individuals with these conditions, and those treatments that may most benefit patients. It is well known among physicians who treat migraine disorders that non-invasive treatment options exist for migraine headaches, yet few are effective in eliminating the condition entirely. Patients continue to suffer despite various short-term treatment regiments, and physicians may be hesitant to proceed to more effective prophylactic solutions, including corticosteroid and local anesthetic injections, botulinum-A...
toxin injections, and surgical decompression at the site where migraine triggers.

This study sought to recruit a large and representative study population using the Amazon Mechanical Turk (AMT) crowdsourcing platform. This method of research is very useful when recruiting study participants where face-to-face interaction is not necessary. Furthermore, this allows researchers to recruit a large number of participants, in a very short period, at a low cost, and in a completely anonymous fashion.\(^3\) The efficacy of collecting longitudinal data in medical research on the AMT platform has been well established in the literature with many tools in place to manage the quality of the data and to screen study participants.\(^3\)\(^-\)\(^7\)

The most common medical treatments available for chronic migraine headaches often include a combination of the following: avoidance of common migraine triggers, prophylactic pharmacologic agents, and various forms of medical pain management therapies.\(^8\)\(^-\)\(^11\) Medical therapy provides patients with some degree of control over the occurrence of their migraines, yet complete elimination in the long term is very unlikely.\(^8\) Alternative options, such as injections of corticosteroids, local anesthetics, or botulinum toxin at migraine trigger sites, may prove to be much more effective at preventing the occurrence of chronic migraine headaches.\(^12\)\(^,\)\(^13\)

Headache disorders often involve occipital and neck pain, which suggests that nerves such as the greater occipital nerve may be involved in the activation and spread of migraines.\(^14\)\(^,\)\(^15\) Modern literature has demonstrated that performing greater occipital nerve block with corticosteroid and anesthetic solution is very effective at reducing the frequency, duration, and intensity of migraines.\(^14\)\(^-\)\(^17\)

Other migraine trigger sites that include the lesser occipital nerve, supratrochlear nerve, supraorbital nerve, sphenopalatine ganglion, and auriculotemporal nerve can also be targeted through injection treatment and have been indicated as a precursor to surgical intervention.\(^18\)\(^-\)\(^20\)

Even in the case of nerve blockade, complete elimination is unlikely, and surgical decompression remains the best option for attempting to entirely prevent the recurrence of migraine headaches.\(^8\)\(^,\)\(^12\) As such, the primary goal of this study was to assess the opinion of patients with migraine toward invasive treatment options such as injection therapy and surgical decompression. This may aid physicians in understanding the needs of their patients so as to better address patient worries prior to proceeding to injection therapy or surgical decompression.\(^21\) With this up-to-date information, it may be possible to subside patients’ fears and provide better care to those who suffer from migraine headaches.\(^8\)\(^,\)\(^21\) As a secondary endpoint, we also sought to assess the current prevalence of self-reported migraine headaches and the disparities that may exist across age, sex, employment, and marital status. Although this information is copiously published on a yearly basis, comparison of anonymous and self-reported diagnoses of migraine disorders with the currently accepted prevalence of these disorders may prove useful.\(^22\)\(^,\)\(^23\) For example, some have shown that although prevalence studies have demonstrated an average prevalence rate of approximately 12%, neurologists have reported a significantly higher number of between 27.6% and 48.6%.\(^24\) Therefore, it is important to assess the disparity between what a patient believes to be a migraine disorder from that of a clinically diagnosed disorder.

This study may be especially relevant to plastic surgeons across the country who are interested in treating patients with chronic migraines or headaches. Botulinum-A toxin injection therapy, corticosteroid and anesthetic injections, and subsequent surgical decompression have been rising in popularity among patients with chronic migraine disorders, thus the results of this study are increasingly relevant to plastic and reconstructive surgeons.\(^13\)\(^,\)\(^25\)\(^-\)\(^27\) A vast body of literature exists in the investigation of botulinum-A toxin use for the treatment of migraine disorders; however, very little attention has been given to innovative treatments such as occipital, supraorbital, supratrochlear nerve block, or sphenopalatine ganglion block with corticosteroids and local anesthetic.\(^28\)\(^-\)\(^32\) As such, our study will focus on the significant role these treatment options may play in the future of migraine therapy and clinical course.\(^32\) Furthermore, the patient opinions presented in this study may also be relevant to other plastic surgical interventions that target complex disorders such as in congenital defect repair.

**METHODS**

In this study, a prospective cross-sectional study was conducted of volunteers recruited through an internet crowdsourcing services, AMT, over the course of 1 month (July 1-August 1, 2018) using a survey instrument (Supplementary Appendix A).\(^5\) Several studies have demonstrated that the worker population is extremely representative of the US internet population, with 70% to 80% of workers from the United States.\(^33\)\(^,\)\(^34\) Workers were provided with a level of compensation and estimated the time of completion, and were screened by Amazon for quality responses. We did not allow workers with lower than a five-star worker rating (the maximum possible score) from participating in the survey. Motivation has been shown to be almost entirely from enjoyment (internally motivated), and thus this has demonstrated a lower bias in the selection of participants who actually completed the survey.\(^6\)\(^,\)\(^33\)

AMT workers are required to be over the age of 18 and registered through the Amazon service platform to prevent individuals from taking the same survey multiple times.
times. Amazon also tracks IP addresses and worker IDs to prevent multiple responses from the same user who may control numerous worker accounts. Surveys were open to 100 people at a time for approximately 24 hr (repeated 10 times) and workers were paid $0.05 per unique response. This allowed us to screen for quality and completeness before proceeding to collect more data. Internet crowdsourcing is a powerful tool in its ability to elucidate the ideas and opinions from a diverse group of individuals that may otherwise be inaccessible through other surveying tools.35 Using the internet to administer surveys significantly reduces costs, response times, and barriers to access specific patient populations.4,6 Owing to the nature of AMT workers disclosing no self-identifying information and not being patients at our institution, institutional review board approval for this study was not sought or necessary. However, the principles from the Declaration of Helsinki were still upheld throughout the course of this study.

Crowdsourcing was utilized to gain survey responses to analyze both the prevalence of self-reported migraine headaches across the United States population and patient opinions regarding adverse outcomes of invasive treatment options for migraine headaches. These adverse outcomes were divided into two groups: those associated with corticosteroid and local anesthetic injection therapy, and those associated with surgical decompression of common migraine trigger sites. Study participants were given a scenario that described one of the two treatment options followed by one or no adverse outcome and were asked to provide a utility score between 0 and 100 mm, with 0 mm (0 cm) representing that the participant would rather be dead and 100 mm (10 cm) representing that the participant would still feel that they were in perfect health. These utility scores were then analyzed across both treatment options and all collected demographics.

Screening Questions

Although AMT requires that registered volunteers be over the age of 18, individuals may not be completely truthful when creating their account. To ensure that all surveyed participants were considered adults, the first questions of the survey asked the participants to reenter their age. No other screening questions were administered to maintain a truly diverse representation of migraine disorders in the United States.

Attention Check Question

To ensure that survey participants were paying close attention to each question and scenario, and also to ensure that the generated data were a valid representation of patient opinions, the following attention check question was included approximately halfway through the survey: “You are given injections on the back of your neck regularly to treat migraines that are painful. These migraines are so painful that the exact answer to this question is 85 regardless of any other information presented in this scenario. The injections help with the migraines, but at the site of the injection you have a raised scar that forms.”

Respondents who entered a number anything other than “85” were directed to the end of the survey and were excluded from this study.35 Those who were excluded were prevented from ever taking this survey again.

Data Analysis

Data from the survey were pooled and assessed using Microsoft Excel 2016 (Redmond, WA). Statistics were performed using TreeAge Pro 2018 (Williamstown, MA) with continuous data evaluated using two-tailed two-sample unequal variances t-tests (alpha = 0.05). The STROBE statement (Supplementary Appendix B) was used as a guideline for assessing the quality of this observational study.

RESULTS

A total of 1095 MTurk participants were interested in the survey. Of these, 697 (64%) were excluded either because they did not meet the inclusion criteria (n = 655) or because they did not complete the survey (n = 42). This is probably due to many workers simply filling out the survey without reading the questions and subsequently failing the attention check. Thus, a total of 398 participants who met the inclusion criteria (screening question and attention check question) with complete responses were included in this study. This screening methodology provides us with the highest quality data from attentive respondents.

Study Participants

A total of 398 individuals with eligible and complete survey responses were included in this study. The MTurk human intelligence system aims to capture a diverse number of study participants, across age, gender, ethnicity, and religion (Table 1). It was found that 98 (25%) of the study participants were between the ages of 18 and 25 years, 144 (36%) were between the ages of 26 and 34, 74 (19%) were between the ages of 35 and 44, and 82 (20%) were 45 years or older. Although a majority of the study participants were female (62%), there were still a large cohort of male participants (38%) included in this
study. A diverse number of religions were also represented (8 in total). A total of 156 (46%) participants stated that they were married, whereas the rest were either divorced (29) or single (213). A majority stated that they were currently employed (77%), and 165 (41%) had children, with an average of 2.04 children per household. Of the 338 participants, 225 stated that they experienced at least 1 headache per month, with the average individual experiencing 4 headaches per month, and 8 total individuals reported experiencing chronic migraine headaches (≥15 headaches per month) (Table 2).

### Migraine Headache Prevalence

The prevalence of migraine headaches as defined by occurring 5 or more times per month, for a duration of 4 to 72 hr, was found to be 15.6% across all study participants (14.6% of males; 16.2% of females; \( P < 0.001 \)) and also varied significantly across age groups.\(^{36} \) Individuals who were between the ages of 26 and 34 years (\( P = 0.02 \)) or over the age of 45 years (\( P = 0.0001 \)) were less likely to experience migraines than those aged 35 to 44 years. However, those aged 18 to 25 years (\( P = 0.03 \)) and 26 to 34 years (\( P = 0.03 \)) were still more likely to experience migraines than those over the age of 45. In fact, individuals under the age of 45 were 2.16 times (95% CI = 1.32-3.53, \( P = 0.0023 \)) more likely to experience migraines than those over the age of 45 (Figure 1A,B).

In addition, the prevalence of all self-reported headache disorders across study participants was found to be 57%, and varied with household income, marital status, and employment status. When isolating household income, minor differences existed between these cohorts, but none was significantly greater or less than the other. The largest
difference existed between the $0 and 25,000 (50% self-reported prevalence) cohort and $50,000 and 75,000 cohort (62% self-reported prevalence), but this relationship was not statistically significant ($P = 0.07$) (Figure 2A).

In relation to gender, 60% of female participants and 51% of male participants self-reported that they experienced headaches, but this relationship was not statistically significant ($P = 0.08$). However, employment status was an excellent predictor that an individual believed they experienced a headache disorder, with 60% of those employed claiming to experience migraines, while only 46% of the unemployed study participants claiming to experience migraine headaches ($P = 0.02$) (Figure 2B).

### Migraine Headache Frequency

The frequency of migraine headaches was defined as the number of self-reported migraine headaches (lasting at least 4-72 hr per episode) experienced per month on average by each study participant. Individuals aged 18 to 25 ($P = 0.0001$), 26 to 34 ($P = 0.0001$), and 45 years or older ($P = 0.00001$) experienced much more frequently than those aged 35 to 44 years (2.73 migraines per month). Similarly, individuals aged 18 to 25 ($P = 0.00001$) and 26 to 34 years ($P = 0.00001$) also experienced more frequent migraines than those aged 45 years or older (3.27 migraines per month).

Although no significant difference in migraine prevalence existed across income, individuals with combined household income of $50,000 to 75,000/year experienced a higher frequency of self-reported migraine headaches when compared with those with incomes of only up to $25,000/year.

### Migraine Headache Severity

The severity of migraine headaches was demonstrated using a horizontal Visual Analog Scale (VAS). Study participants were asked to rate the average severity of their migraines on a scale of 0 to 100 mm, with 0 mm representing the worst pain imaginable and 100 mm representing perfect health. Thus, a lower score indicates a more severe migraine. The VAS of 0 to 100 mm was chosen, as it has been demonstrated to generate more meaningful utility scores than the classic 0 to 10 cm scale commonly used in the practice of neurology (divided into groups of 0-4, 4-44, 45-74, and 75-100 mm).

Migraine severity varied significantly across age and household income (Figure 1C). Individuals aged 18 to 25 ($P = 0.0001$), 26 to 34 ($P = 0.0001$), and 45 years or more ($P = 0.0000003$) experienced much more severe migraine headaches, on average, than those between the ages of 35 and 44 years, with those aged 45 years or more experiencing the most severe headaches (VAS = 44.23).

When comparing those with household incomes of $50,000 to 75,000 with those making less than $25,000/year, the later experienced more severe migraines ($P < 0.000001$). Although employment status was a predictor of the presence of migraine headaches, there was no significant difference in frequency or severity when compared with the unemployed.

### Migraine Symptoms

Among those study participants experiencing self-reported migraine headaches, the vast majority (69%) reported experiencing at least one or more types of symptom, which
has been perceived as an “aura” by the study participants (Figure 3). The most common symptom was a sensitivity to light (72%), followed by a sensitivity to sound (52%) and nausea (48%). The majority of individuals experiencing migraine with symptomatic occurrences (78%) experienced more than one symptom prior to or during their migraine headaches.

**Chronic Migraine Utility Scores**

Study participants were provided a VAS and asked to provide a numerical value (utility score) that would define the severity of various health scenarios. The scale ranged from 0 to 100, with 0 defined as an experience equivalent to death and 100 defined as an experience equivalent to
perfect health. The health scenarios presented to study participants detailed a specific defect or complication that could result from either surgical treatment (hypesthesia, paresthesia, ptosis, incisional alopecia, temporal hollowing, or hematoma) or nonsurgical treatment (vasovagal syncopal attacks, dizziness, local pain, vertigo, needle alopecia) of their migraine headaches. Utility scores did not significantly vary when comparing the responses of study participants who either did or did not experience migraine headaches (Figure 4).

Among those who do not experience migraine headaches, the lowest utility score was found to be for hematoma (47.60), followed by vertigo (52.40). This was also found to be true among those who do experience migraine headaches (Table 3). Study participants demonstrated that they were least concerned with incisional alopecia (V AS = 75.08, no migraines/70.65, migraines) or needle alopecia (V AS = 71.75/70.76).

**DISCUSSION**

The study aimed to assess patient opinions about migraine treatment options, adverse outcomes, and overall sentiment to experiencing migraine disorders. We also sought to provide an update on the prevalence of self-reported headache disorders in the United States, which is often times much greater than that demonstrated by physician-defined prevalence studies. Although the sample size was relatively small ($n = 398$), this study produced meaningful results, demonstrating that the perception of experiencing migraine headaches has increased over the last two decades. This information is critical in better treating and guiding these patients, even those that would not be clinically diagnosed with a migraine disorder.

**Participant Age**

Participants aged 18 to 25 years reported experiencing the most headaches compared with any other age group. This may be due to the increasing number of stressors that impact the young lives of the millennial generation. In fact, millennials make up the largest percentage of individuals working extremely long hours and remaining constantly in touch with society and the internet. Several studies have suggested that this may be secondary to pervasive use of cell phones. One study suggests that extensive cell phone use may cause “text neck,” which may cause strain-related headaches and migraine disorders. Furthermore, cell phone and internet use have been implicated in having a detrimental effect on sleep health, which may further exacerbate headache symptoms and frequency. Millennials also take the fewest breaks or vacations compared with any other age group, yet they make 20% lower annual salaries than any previous generation at the same point of their careers. This high stress, low-reward work, and life balance may result in a higher prevalence of adverse health outcomes such as migraine headaches.

Another major indicator of stress in the United States according to the 2017 APA report on stress was that technology has a very negative impact on the physical and mental health of its users. It is no surprise that the millennial generation is the highest volume user of available...
technology, and almost never takes a break from interacting with these conduits to the digital world.

However, although a larger number of individuals in younger generations experience migraine headaches, they are less frequent and of lower severity than those of older generations. In fact, although individuals over the age of 45 had the lowest prevalence of self-reported migraine headaches, those who did experience migraines at the greatest frequency and severity compared with all other age groups. This may be due to the fact that older individuals experiencing migraines are long-time sufferers or have exhausted many available treatment options. As such, they may experience very severe and uncontrolled migraine headaches. These individuals may thus

Figure 4. Pooled utility scores across those study participants who do not experience headaches (blue) and experience at least one headache per month (orange).

Table 3. Summary of Utility Scores Across All Study Participants (n = 398), and Those Who Reported Having at Least One Migraine Headache per Month (n = 225)
be excellent candidates for invasive options, such as anesthetic and corticosteroid injections, and subsequent surgical decompression.

**Household Income/Employment Status**

In this study, the greatest outlier of migraine frequency and severity existed among those households making between $75,000 and $100,000 per year, yet there was no significant difference in migraine prevalence across income. Those in this income cohort experienced the highest severity migraines, but also least frequently. This relationship correlates well with the 45+ age cohort, with the median household income of individuals aged 45 to 54 years was $61,111 in 2017. However, the mean income of each member of the household was only $27,924, which cause significant stress among individuals living in such households. Although millennials have a mean household income of only $35,592, the $25,000 to $50,000 income cohort reported the lowest severity migraine headaches. These relationships may demonstrate that income plays an important role in the occurrence of migraine headaches among older individuals, but that millennials may not find annual income as a significant stressor.

Not surprisingly, employment status was an important predictor of migraine headaches. Hundreds of studies have found that job stress is the major source of stress for American adults, and this has been increasing significantly over the past two decades. Increased work-related stress has been demonstrated to be associated with adverse health outcomes, with migraine headaches serving as an accurate indicator of poor stress management.

**Migraine Treatment Options**

The primary endpoint of this study was to define the fears and sentiment associated with what patients would believe are more “extreme” treatment options for migraine headaches. As such, study participant’s feelings toward adverse health outcomes of two major treatment options were investigated—anesthetic/corticosteroid injections of implicated nerves, and surgical decompression of migraine trigger points. Those individuals who do experience migraine headaches were less fearful of minor complications (vertigo, local pain, and dizziness), but more fearful of major complications such as hematoma, temporal hollowing, ptosis, and para/hypesthesia of the face. As such, physicians interested in offering more advanced treatment options for migraine headaches should focus on quelling fears focused on “worst possible” outcomes, rather than the minor complications often associated with these procedures.

In addition, the most feared complication among migraine sufferers (hematoma) was only rated on average 44.79 on the VAS. This demonstrates that patients may not be as fearful of adverse outcomes as once thought, but other barriers to healthcare such as uncertainty of success or treatment costs may be holding patients back from pursuing aggressive treatment options. The benefits of surgical intervention or injection therapy may very well outweigh the possible adverse outcomes associated with these treatments. It is important for physicians who hope to offer these interventions to make the overarching benefits a priority in the discussion with patient. It follows that the overarching results of utility surveying indicate that patients seem willing to undergo riskier interventions for more successful clinical outcomes. However, a major limitation of this study was an inability to accurately assess whether participants understood the health scenarios that were provided. To avoid any misinterpretations, a large amount of detail was provided in lay terms to study participants.

Even so, participants still misinterpreted several facets of their headache disorders. For one, the true rate of migraine prevalence was found to be only 15.6% among all study participants but was self-reported to be 57%. This vast disparity indicates that many patients are misinformed and misdiagnosed about their headaches, and as a result may be treating their condition incorrectly. These results may help motivate physicians to better educate their patients and formulate more patient-centered treatment options. This is especially important in the chronic pain care setting, where it has been shown that better patient education and patient-centered treatment has led to the greatest reduction in morbidity. As such, diagnosis by a certified headache neurologist should be recommended prior to consideration of any of the treatment options discussed in this article, as patients may be misinterpreting their headache symptoms that may more accurately be a reflection of tension headaches, daily persistent headaches, or occipital neuralgia. Various pathologies respond differently to invasive and noninvasive treatments, and a differential should be considered and discussed with the patient to avoid mistreatment.

**Limitations**

A potential limitation of using Amazon MTurk may be that a single study participant could submit multiple survey responses. Individuals could also circumvent the survey process completely, by using a random number generator to create survey completion codes that are required for study participants to claim their wages. However, this did not have an impact on the study results—all surveys were screened for completeness, accuracy, and uniqueness (IP address and worker ID screening).

Another potential limitation of this study, and inherent to many surveying methodologies, is an internal bias that
exists among individuals who chose to take the survey and reimbursement for their participation. Migraine sufferers may have been more likely to choose and complete the survey than nonmigraine sufferers, and the level of compensation may also influence this decision. To try and avoid this bias, migraines were not mentioned in the survey title or description. However, despite these limitations, MTurk remains a powerful tool for surveying the US population, and can be an excellent indicator of patient opinions, fears, and sentiment toward healthcare scenarios and treatment options.

CONCLUSIONS

This study serves as an important update on self-reported migraine prevalence in the United States. As indicated by the results of the survey instrument, migraine headaches remain a major cause of morbidity across all ages, gender, and socioeconomic statuses, with almost two in three Americans self-reporting that they suffer from migraines, and with 15.6% of these that fall under the diagnostic criteria of a migraine disorder. The millennial generation may be responsible for the increasing prevalence of headache disorders, due to the high stress of modern society and the modern workplace, and an increasingly pervasive digital environment.

This study also defines the fears patients may have in the pursuit of invasive treatment options for migraine headaches. The data demonstrate that patients may not be as fearful of adverse outcomes, but rather the uncertainty of successful outcomes, or increasing treatment costs that may be limiting patient care. Physicians interested in offering minimally invasive or surgical treatment options for migraine headaches should thus focus on addressing these barriers to care when consulting patients.

Supplementary Material

This article contains supplementary material located online at www.asjopenforum.com.

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