HEADACHE & FACIAL PAIN SECTION

Original Research Article

Factors Related to Migraine Patients’ Decisions to Initiate Behavioral Migraine Treatment Following a Headache Specialist’s Recommendation: A Prospective Observational Study

Mia T. Minen, MD, MPH,*† Sarah Azarchi, BS,‡ Rachel Sobolev, BA,§ Amanda Shallcross, ND, MPH,¶ Audrey Halpern, MD,* Thomas Berk, MD,* Naomi M. Simon, MD,§ Scott Powers, PhD,‖ Richard B. Lipton, MD,* and Elizabeth Seng, PhD,kj

*Department of Neurology, †Department of Population Health, and §Department of Psychiatry, NYU Langone Medical Center, New York, New York; ‡NYU School of Medicine, New York, New York; ¶Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children’s Hospital, Cincinnati, Ohio; ‖Department of Neurology, Albert Einstein College of Medicine, Bronx, New York; kjFerkauf Graduate School of Psychology, Yeshiva University, Bronx, New York, USA

Correspondence to: Mia T. Minen, MD, MPH, Department of Neurology, NYU Langone Medical Center, 240 East 38th Street, 20th Floor, New York, NY 10016. Tel: 212-263-7744; Fax: 212-263-7721; E-mail: minenmd@gmail.com.

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Abstract

Objective. To evaluate the frequency with which migraine patients initiated behavioral migraine treatment following a headache specialist recommendation and the predictors for initiating behavioral migraine treatment.

Methods. We conducted a prospective cohort study of consecutive patients diagnosed with migraine to examine whether the patients initiated behavioral migraine treatment following a provider recommendation. The primary outcome was scheduling the initial visit for behavioral migraine treatment. Patients who initiated behavioral migraine treatment were compared with those who did not (demographics, migraine characteristics, and locus of control) with analysis of variance and chi-square tests.

Results. Of the 234 eligible patients, 69 (29.5%) were referred for behavioral treatment. Fifty-three (76.8%) patients referred for behavioral treatment were reached by phone. The mean duration from time of referral to follow-up was 76 (median 76, SD = 45) days. Thirty (56.6%) patients initiated behavioral migraine treatment. There was no difference in initiation of behavioral migraine treatment with regard to sex, age, age of diagnosis, years suffered with headaches, health care utilization visits, Migraine Disability Assessment Screen, and locus of control (P > 0.05). Patients who had previously seen a psychologist for migraine were more likely to initiate behavioral migraine treatment than patients who had not. Time constraints were the most common barrier cited for not initiating behavioral migraine treatment.

Conclusions. Less than one-third of eligible patients were referred for behavioral treatment, and only about half initiated behavioral migraine treatment. Future research should further assess patients’ decisions regarding behavioral treatment.
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Migraine is a chronic disabling neurological condition characterized by episodic attacks of moderate to severe head pain and associated symptoms of nausea/vomiting and sensitivity to light and sound. Three types of behavioral headache treatments are considered level A evidence-based treatments for migraine: relaxation, biofeedback, and cognitive behavioral therapy (CBT) [1]. In addition to being effective (defined as resulting in at least a 50% reduction in headache days), these treatments are safe and well tolerated [1]. Behavioral treatments have enduring benefits [2] and may be less costly than pharmacologic interventions [3]. However, suboptimal adherence may diminish the efficacy of these behavioral therapies, and prior research has shown that premature termination of psychotherapy, or psychotherapy dropout, is generally recognized as a significant barrier to the delivery of effective care. For example, reviews of the psychotherapy dropout literature and data from the National Institute of Mental Health indicate that between 30% and 60% of psychotherapy outpatients terminate prematurely [4]. While there have been some data examining dropouts in patients already engaging in CBT for migraine [5], surprisingly little attention has been devoted to understanding factors associated with initiating behavioral migraine treatment following physician recommendation in typical clinical practice [6,7]. Furthermore, prior research examining psychotherapy dropouts has typically investigated patient and therapist demographic characteristics, but demographic variables were generally not related to dropout. As far back as 1993, Wiercik and Pekarik stated that dropout researchers should focus their efforts on investigating other variables [4]. A meta-analysis of 11 studies found a moderate association between psychotherapy dropout and therapeutic alliance in adult individual psychotherapy [8]. Studies that have investigated more complex variables, such as patients’ intentions and expectations, have found them to be far more powerfully associated with dropout than simple patient and therapist variables [9–12]. This is especially important because prior research has shown that many patients with chronic pain referred for behavioral treatment are not prepared to engage in behavioral treatment [13,14].

Thus, we sought to better understand factors related to initiating behavioral migraine treatment following a physician recommendation. More specifically, we sought to examine both patient migraine characteristics (e.g., disability) and patient beliefs using headache-specific locus of control (HSLC) and headache management self-efficacy (HMSE). HSLC refers to what the patient believes is primarily responsible for the onset and course of migraine [15]. In the broader health literature, higher health care profession locus of control has been associated with greater utilization of medical (as opposed to behavioral) treatments for chronic health conditions [16,17]. Self-efficacy has been shown to be an important determinant of adherence to treatment recommendations in a variety of conditions [18,19]. Thus, both locus of control and self-efficacy could be important in identifying patients more or less likely to initiate behavioral migraine treatment in a naturalistic setting. We also sought to determine perceived barriers to behavioral therapy.

Methods

This was a prospective observational study that took place among headache specialists affiliated with an urban academic medical center in New York City. The study was approved by the NYU Langone Medical Center Institutional Review Board (Study i16-00937).

Participants were recruited consecutively between July 19, 2016, and March 17, 2017. Four headache fellowship-trained physician headache specialists took part in the study. They participated for varying periods spanning anywhere from one to eight months. Inclusion criteria were age 18 years and older and diagnosis of migraine by a fellowship-trained headache specialist based on the International Classification of Headache Disorders (ICHD–3 beta criteria [20]. Additional criteria were that they were willing to participate and sign the informed consent form. All of the consecutive migraine patients were provided the option to enroll in the study, regardless of whether they were referred for behavioral therapy, so that we could also determine the overall rate of patients in our center referred for migraine behavioral treatment.

For the purpose of this study, a referral for behavioral treatment was defined by documentation that a headache physician counseled the patient to see a therapist trained in one or more of the following modalities: CBT, biofeedback, and/or relaxation training. Referral was made at the discretion of the headache specialist, and the referral was for behavioral therapy for migraine specifically. As psychologists often decide which treatment modality is best for the patient and they commonly choose a combination of treatment modalities, we did not assess which type of level A evidence-based behavioral treatment the patients were referred to. This was per the recommendation of health psychologists whom we consulted regarding the study design (including the senior author of this study). In this practice, patients were generally referred to a health psychologist or psychologist who had a special focus in behavioral treatment for headache. Patients were told that the purpose of the study was to assess what happens after their visit with the headache specialist; they were not told it was...
to assess whether they adhered to the recommendation to initiate behavioral treatment specifically.

This was a mixed methods study. After informed consent was obtained, patients were asked to complete a paper questionnaire at the end of the visit. The survey included questions about demographics, headache history and disability (the Migraine Disability Assessment Screen [MIDAS]), and prior health care utilization. Patients also completed validated measures of headache locus of control and headache management self-efficacy (see Measures for descriptions of these scales). Referral to behavioral treatment was determined by a form on which the headache specialist marked down whether the patient was referred for behavioral treatment. If there were any missing data, a study member (AB) collected the data from the provider’s note in the electronic medical record. A follow-up structured interview was administered two to three months after the appointment via phone. Patients were not informed ahead of time about the content of the follow-up questions. During the call, patients were asked 1) whether they had made an initial appointment for the behavioral migraine treatment and 2) reasons for taking part or not initiating behavioral migraine treatment.

Data were entered into RedCap [21] by a study team member (AB). Data quality checks were conducted by a team of two other study team members (RS and SA) to ensure that there was high data accuracy and no inputting errors.

**Measures**

The Migraine Disability Assessment [22] is a validated five-item questionnaire that has internal consistency and test-retest reliability and was developed to assess headache-related disability with the goal of improving migraine care. Questions ask about prior activity limitations over the past three months. Examples include “On how many days in the last 3 months did you miss work or school because of your headaches?” and “On how many days in the last 3 months did you miss social or leisure activities because of your headaches?”

The HSLC [15,23] is a 33-item self-report measure with good internal consistency and adequate test-retest reliability assessing beliefs about the development and progression of headache symptoms and whether they are a result of their own behaviors, their medical professional’s actions, or due to chance. The ratings involve a five-point Likert scale (1 = strongly disagree to 5 = strongly agree). There are three subscale scores: internal HSLC, chance HSLC, and health care professional HSLC. Items include “When I worry or ruminate about things I am more likely to have headaches” (internal), “It’s a matter of fate whether I have a headache” (chance), and “My headaches can be less severe if medical professionals (doctors, nurses, etc.) take proper care of me” (medical professionals). Internal scores were reverse-coded.

The HMSE [24] is a 25-item self-report measure with high internal consistency and construct validity that assesses level of confidence in managing headache pain and preventing headache episodes. The ratings involve a seven-point Likert scale (1 = strongly disagree to 7 = strongly agree). Higher scores are associated with increased use of positive psychological coping strategies used in preventing and managing headaches. Examples of items include “I can reduce the intensity of a headache by relaxing” and “If I am under a lot of stress, there is nothing I can do to prevent the headaches.” Certain items were reverse-scored.

**Analyses**

**Quantitative**

Descriptive statistics including means and standard deviations are reported. In addition, patients who scheduled behavioral treatment were compared with those who did not across categories including demographics, migraine characteristics, and personal beliefs using one-way between-groups analysis of variance and chi-square tests. Two-tailed tests were performed, and alpha was set at 0.05 for all analyses. SPSS version 23 and GraphPad were used for all statistical analyses.

**Qualitative**

Study members SA and RS documented responses to the structured interview in a RedCap questionnaire in real time. General thematic analysis [25] was used to analyze the reasons that patients who were referred to behavioral treatment adhered or did not adhere to the recommendation to schedule an appointment with a provider. SA and RS individually created a list of codes that emerged from responses to each question. The individual code lists were compared and combined to establish a universal code. SA and RS each used the universal code to assign codes to the respondent data, and then reconciled the coding. Discrepancies were resolved by MTM. The authors of this paper carefully evaluated the codes to achieve agreement on themes and subthemes. Multiple patients received more than one code.

**Results**

A total of 234 patients were enrolled in the study. Of those, 69 (29.5%) were referred for behavioral treatment. Fifty-three (76.8%) of the patients referred for behavioral treatment completed the follow-up structured interview. The mean duration (SD) from the time of enrollment to the follow-up phone call was 76 (45) days. Just over half of patients referred (56.6%, N = 30) initiated behavioral migraine treatment. Table 1 compares the patients who initiated behavioral migraine treatment (N = 30) and those who did not (N = 23). The two groups were similar with regard to sex, age, age of
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### Table 1  Demographics and prior health care utilization

<table>
<thead>
<tr>
<th>Factor</th>
<th>Overall (N = 53)</th>
<th>Attended Behavioral Treatment (N = 30)</th>
<th>Did Not Attend Behavioral Treatment (N = 23)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>38.6 ± 13.2</td>
<td>39.4 ± 14.0</td>
<td>37.7 ± 12.2</td>
<td>0.636</td>
</tr>
<tr>
<td>No. of females</td>
<td>42 (79.2%)</td>
<td>26 (86.7%)</td>
<td>16 (69.6%)</td>
<td>0.128</td>
</tr>
<tr>
<td>Age of diagnosis, y</td>
<td>25.4 ± 4</td>
<td>27.6 ± 13.2</td>
<td>22.5 ± 10.2</td>
<td>0.129</td>
</tr>
<tr>
<td>Age of first headache, y</td>
<td>15.4 ± 8.2</td>
<td>16.9 ± 9.9</td>
<td>13.5 ± 5.1</td>
<td>0.143</td>
</tr>
<tr>
<td>Past behavioral treatment for headache</td>
<td>Prior CBT</td>
<td>10 (19.2%)</td>
<td>8 (26.7%)</td>
<td>0.112</td>
</tr>
<tr>
<td></td>
<td>Prior Biofeedback Treatment</td>
<td>8 (15.4%)</td>
<td>7 (23.3%)</td>
<td>0.064</td>
</tr>
<tr>
<td></td>
<td>Prior PMR Therapy</td>
<td>2 (3.8%)</td>
<td>2 (6.7%)</td>
<td>0.210</td>
</tr>
<tr>
<td></td>
<td>Prior CBT, Biofeedback, and/or PMR Treatment</td>
<td>14 (26.4%)</td>
<td>11 (36.7%)</td>
<td>0.054</td>
</tr>
<tr>
<td>Saw a Psychologist</td>
<td>9 (17.3%)</td>
<td>9 (30.0%)</td>
<td>0 (0.0%)</td>
<td>0.004</td>
</tr>
<tr>
<td>Saw a Psychologist and/or reported doing CBT, Biofeedback, and/or PMR previously</td>
<td>18 (34.0%)</td>
<td>15 (50.0%)</td>
<td>3 (13.0%)</td>
<td>0.005</td>
</tr>
<tr>
<td>Past providers seen for evaluation and/or treatment of their headaches</td>
<td>Acupuncturist</td>
<td>15 (28.8%)</td>
<td>10 (33.3%)</td>
<td>0.404</td>
</tr>
<tr>
<td></td>
<td>Chiropractor</td>
<td>10 (19.2%)</td>
<td>8 (26.7%)</td>
<td>0.112</td>
</tr>
<tr>
<td></td>
<td>Dentist</td>
<td>12 (23.1%)</td>
<td>7 (23.3%)</td>
<td>0.959</td>
</tr>
<tr>
<td></td>
<td>Emergency Department Provider</td>
<td>19 (36.5%)</td>
<td>10 (33.3%)</td>
<td>0.575</td>
</tr>
<tr>
<td></td>
<td>Ophthalmologist</td>
<td>22 (42.3%)</td>
<td>12 (40.0%)</td>
<td>0.694</td>
</tr>
<tr>
<td></td>
<td>Otolaryngologist</td>
<td>12 (23.1%)</td>
<td>8 (26.7%)</td>
<td>0.473</td>
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<td>Physical Therapist</td>
<td>8 (15.4%)</td>
<td>7 (23.3%)</td>
<td>0.064</td>
</tr>
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<td></td>
<td>Primary Care Doctor, Family Medicine Doctor, or Pediatrician</td>
<td>44 (84.6%)</td>
<td>26 (86.7%)</td>
<td>0.632</td>
</tr>
<tr>
<td></td>
<td>Psychiatrist</td>
<td>5 (9.6%)</td>
<td>4 (13.3%)</td>
<td>0.288</td>
</tr>
</tbody>
</table>

Continuous variables reported as mean ± standard deviation.
Categorical variables reported as frequency.

CBT = cognitive behavioral therapy; PMR = progressive muscle relaxation.

diagnosis, age of first headache, years suffered with headaches, health care utilization visits, and MIDAS (P > 0.05). The only statistically significant difference was seen for patients who had previously seen a psychologist for their migraines. There was a significant difference in those who initiated behavioral therapy based on whether they had previously seen a psychologist (30%) or not previously seen a psychologist (0%, P = 0.004). In addition, as seen in Table 2, locus of control was not associated with adherence.

Qualitative analysis identified several themes related to initiating behavioral migraine treatment following physician recommendation (Table 3). Several patients provided multiple reasons for initiating (or not initiating) behavioral migraine treatment, indicating that for any individual patient, multiple factors may have played a role in the decision. Of the patients who did not initiate behavioral migraine treatment (N = 23), half cited time limitations as a barrier to adherence. In addition to the time limitation, patients did not initiate behavioral therapy for migraine for reasons including cost, skepticism that it would work, contentment with their current treatment plan, and satisfaction that their headaches were already improving.

**Discussion**

Behavioral treatments are a first-line, well-tolerated treatment for migraine [1]. However, little is known about how frequently patients initiate behavioral migraine treatment following a physician recommendation or what factors are associated with initiation of behavioral migraine treatment. In this study examining patients in a physician headache specialty practice, only about half of the patients with migraine who were referred actually initiated behavioral migraine treatment within two to three months. The primary reported barrier to initiating behavioral migraine treatment was concern about the time commitment. Other reported barriers included cost (including concerns about insurance coverage) and the...
perception that additional behavioral treatment would not add to current behavioral treatment or self-management practices. This points to the need for a shift in patient expectations regarding the importance of engaging in behavioral treatment as part of a comprehensive, patient-centered migraine management plan and a systems-based approach to reducing barriers to accessing evidence-based behavioral treatment for migraine.

In this study, approximately half (56%) of patients referred by their physician initiated behavioral migraine treatment. This finding converges with previous evidence from the broader migraine adherence literature, which has suggested that only 60% of patients adhere to migraine appointment attendance, regardless of provider or treatment type [26]. Together, these findings highlight broad problems with treatment adherence among patients with migraine [27] and underscore the importance of implementing adherence facilitation strategies (e.g., thoughtful and nonstigmatizing patient education, involving the patient in treatment planning, and initiating discussions about barriers, etc.) when...
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by the MIDAS) and locus of control. The majority (76.8%) of the patients referred for behavioral treatment (N = 69) were successfully reached during a follow-up call.

This study has a number of limitations. Study participants were seeking treatment at an academic headache center. Thus, results may not be generalizable to patients outside of this setting. However, it is likely that patients who come to see headache specialists may be more likely to pursue behavioral migraine treatment because of greater migraine-related disability compared with patients presenting in non-specialty care settings. They may be additionally more likely to pursue behavioral treatment because a headache specialist might be better able to explain the advantages of behavioral treatment given their extensive training in headache medicine [31]. Thus, the need to enhance receipt of behavioral treatment may be even greater than reported.

In addition, while migraine disability (measured by the MIDAS) indicated the significant impact of migraines on patients’ lives, future studies would benefit from also examining headache days. There was a prolonged duration between study enrollment and the follow-up call. This would have given patients additional time to pursue the recommendation for behavioral treatment and might have increased the number who reported going for behavioral treatment. The sample size for certain subgroup analyses (i.e., previous experience with behavioral headache treatment) was small. Also, this was a pragmatic study in which we examined the patients referred for behavioral treatment. We did not seek to examine what would happen if all patients presenting to a headache center were referred for behavioral treatment, which might result in even lower adherence rates. It is not always necessary nor economically appropriate to send all referrals for behavioral treatment. Also, in this way, those referred were referred because their headache specialist thought that behavioral treatment was appropriate, and thus the headache specialist would be most willing to show their support for the recommendation of referral to behavioral treatment.

Finally, we only sought to determine whether patients scheduled an initial appointment for behavioral treatment, the first step in the process to getting behavioral treatment. Those who did not would be considered those who “rejected” therapy. We do not know whether those scheduled the appointment showed up to the appointment, nor do we know the extent to which they participated in behavioral treatment. Nonadherence rates of behavioral treatment for various disorders are high, with dropout rates of up to 20–47% depending on the disorder being treated [4,33]. Thus, the rate of completion of an adequate “dose” of behavioral treatment is likely even less than the adherence rate for initiation reported.

Future Directions

We were unable to identify any meaningful patient variables associated with adherence to behavioral treatment

recording any new migraine treatment strategy [26,28]. Behavioral treatments are associated with pain reduction, improvements in quality of life and medication adherence, and reduced psychiatric comorbidity [29]. However, behavioral treatments are only effective when patients both initiate treatment and engage in the behavior change strategies recommended throughout treatment. Studies examining adherence rates to specific behavioral treatment recommendations (e.g., diet, exercise, sleep, cognitive and behavioral strategies for relaxation and stress management) among patients with headache are underrepresented in the literature. Extant evidence indicates that adherence rates range from 32–72% and may vary based on treatment regimen examined and the definition and measurement of adherence (for a review, see Ramsey et al. [28]). Understanding how to optimize patient adherence to each step of behavioral treatments, from initiation through behavior change strategies, is a critical next step.

Health system strategies may be a fruitful area for future growth in improving initiation of migraine behavioral treatment. Many people with migraine likely benefit from the lifestyle modification that behavioral treatment engenders [30,31]. Skills taught in behavioral treatments, such as stress management, sleep management, and self-care around migraine attacks, would likely benefit all people with migraine. Further, behavioral treatment techniques can directly enhance the effectiveness of medical interventions by promoting adherence to preventive and acute medications, appointment-keeping with medical providers, and overall integration of migraine management into daily living. Thus, identifying strategies to increase access to behavioral treatments for all people with migraine, as well as initiation of behavioral migraine treatment following physician referral, is an important area of further inquiry.

Interestingly, those who did not attend behavioral treatment were accessing other aspects of the health care system. The vast majority (>80%) had consulted with a primary care physician, over 40% had been to the ED for headaches, and over 40% had consulted with an ophthalmologist regarding the headaches. This suggests that patients perceived greater barriers to accessing behavioral, compared with medical treatments for migraine [32]. Further efforts to enhance access to behavioral treatments, including co-located and referral-based models, as well as efforts to enhance insurance reimbursement for these evidence-based strategies, could be fruitful future directions to reduce these barriers and improve migraine patient care on a public health level. Telehealth and Internet or app-supported interventions might be developed to decrease the time needed to attend appointments if patients are concerned about the time commitment.

Strengths of this study included the ability to recruit from an urban medical center that serves a broad demographic of patients. The extensive initial in-office survey allowed us to capture information about patients’ history of migraine management/treatment, disability (represented by the MIDAS), and locus of control. The majority (76.8%) of the patients referred for behavioral treatment (N = 69) were successfully reached during a follow-up call.

This study has a number of limitations. Study participants were seeking treatment at an academic headache center. Thus, results may not be generalizable to patients outside of this setting. However, it is likely that patients who come to see headache specialists may be more likely to pursue behavioral migraine treatment because of greater migraine-related disability compared with patients presenting in non-specialty care settings. They may be additionally more likely to pursue behavioral treatment because a headache specialist might be better able to explain the advantages of behavioral treatment given their extensive training in headache medicine [31]. Thus, the need to enhance receipt of behavioral treatment may be even greater than reported.

In addition, while migraine disability (measured by the MIDAS) indicated the significant impact of migraines on patients’ lives, future studies would benefit from also examining headache days. There was a prolonged duration between study enrollment and the follow-up call. This would have given patients additional time to pursue the recommendation for behavioral treatment and might have increased the number who reported going for behavioral treatment. The sample size for certain subgroup analyses (i.e., previous experience with behavioral headache treatment) was small. Also, this was a pragmatic study in which we examined the patients referred for behavioral treatment. We did not seek to examine what would happen if all patients presenting to a headache center were referred for behavioral treatment, which might result in even lower adherence rates. It is not always necessary nor economically appropriate to send all referrals for behavioral treatment. Also, in this way, those referred were referred because their headache specialist thought that behavioral treatment was appropriate, and thus the headache specialist would be most willing to show their support for the recommendation of referral to behavioral treatment.

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Future Directions

We were unable to identify any meaningful patient variables associated with adherence to behavioral treatment

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recommendations among this group of patients with migraine for whom the headache specialist felt behavioral treatment was an appropriate intervention. This was particularly surprising for the locus of control; we had expected that individuals who had high expectations that medical professionals are primarily responsible for migraine management may be less likely to adhere to behavioral treatment recommendations and that individuals with high expectations that their own actions are primarily responsible for migraine management would be more likely to adhere to behavioral treatment recommendations. Future research should evaluate other potentially relevant patient variables that could be associated with adherence to behavioral treatment recommendations, particularly those that are related to the barriers described in the qualitative results: perceptions related to business, stress, and financial considerations.

Further, in this investigation, time constraint was the most frequently cited barrier for not adhering to the recommendation for behavioral treatment. Future studies are needed to replicate this finding and to further explore these factors. Accessible and affordable evidence-based behavioral therapies are needed for patients seeking evidence-based pain management treatment. Time-limited and minimal-contact therapies have demonstrated efficacy for treating migraine [34]. Technology-assisted behavioral treatments are gaining evidence in migraine [35,36] and other conditions [37]. Future research should continue to evaluate methods to reduce the impact of time constraint on initiating behavioral migraine treatment. Future studies must also assess the minimum dose needed to be effective for migraine prevention. In addition, future studies might examine whether patients are pursuing some of the emerging behavioral therapies for migraine such as mindfulness and acceptance and commitment therapy [38–41]. Given concerns about migraine and stigma, research on whether stigma plays a role in limiting patients’ ability to access migraine behavioral treatment might also be explored [42,43].

Finally, the way in which providers discuss behavioral treatment with patients deserves further exploration [31]. Providers who are knowledgeable about behavioral treatment are more likely to be effective in explaining the rationale for behavioral treatment and more likely to be effective in referring patients for the treatment. In essence, evidence-based behavioral therapies should be presented to patients in a similar way in which pharmacologic therapies are presented, with attention to methodologies to enhance and confirm adherence [31].

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