



## Delayed opportunities for patient-provider communication about medication overuse headache: Mixed methods perspectives from patients and neurologists

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### ABSTRACT

**Objectives:** Medication overuse headache (MOH) is a common, debilitating condition occurring when migraine patients overuse pain relief medications. We conducted a convergent mixed methods study examining patient-provider communication on MOH.

**Methods:** Migraine patients were identified from one academic health center via electronic health records. Research staff recruited patients and administered a remote survey on MOH awareness, knowledge, and communication; descriptive and bivariate analyses were conducted. Neurologists from the same health center were invited to participate in qualitative interviews; analysis drew from the Rapid Identification of Themes from Audio Recordings procedures. A side-by-side comparison of results followed.

**Results:** Participants included 200 patients and 13 neurologists. More than one third of patients (39.5 %) had never heard of 'medication overuse headache.' Among those who had, 38.4 % learned about MOH  $\geq$  5 years after their migraine diagnosis. Neurologists similarly reported limited patient awareness of MOH and suggested communication was provider-initiated, reactive to patient-reported symptoms and behaviors. Participants agreed MOH was described as a 'consequence' of frequent medication taking, though specific terminology varied with neurologists suggesting they choose terms they perceive to be easier to understand and less stigmatizing to patients. Neurologists felt they lacked effective patient education resources.

**Conclusions:** Findings reveal delayed opportunities to inform patients about MOH. Standardized education supporting early preventive communication is needed, perhaps in primary care where many patients seek initial care for migraine symptoms.

### 1. Introduction

Medication overuse headache (MOH) is a common condition, affecting more than 63 million adults worldwide and up to 30–50 % of patients in headache specialist centers (Cheung et al., 2015). MOH occurs when patients with a pre-existing headache disorder over time experience decreased effectiveness of acute pain relief medication to treat symptoms, causing increased number and severity of headache days and, in turn, further increased use of acute medication; this cyclic process results in additional headaches and can contribute to the

development of chronic migraine (Wakerley, 2019). MOH is debilitating for many and has been linked to higher rates of anxiety and depression, and poor health-related quality of life (Wakerley, 2019; Schwedt et al., 2021; Benz et al., 2017).

Guidelines recommend providers educate patients on the condition, increasing patient awareness of the consequences of medication overuse, ways to avoid MOH, and when to seek clinical care (Wakerley, 2019). Limited research has examined patient-provider communication practices related to MOH, or how practices might be enhanced (Patwardhan et al., 2007; Andrasik et al., 2009). Previous research has been

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primarily conducted in Europe and shown many providers fail to discuss MOH with patients; consequently, patients are often unaware and lack requisite knowledge needed for MOH prevention (Kristoffersen and Lundqvist, 2014; Rapoport, 2008; Lai et al., 2014).

To advance this research, we conducted a convergent mixed methods study on patient-provider communication about MOH in a large academic health center in the United States (US). Specifically, we conducted a structured survey with migraine patients alongside qualitative interviews with practicing neurologists. We aimed to understand current MOH communication practices and needs.

## 2. Methods

### 2.1. Participant recruitment and enrollment

Patients and neurologists from an academic health center in and around Chicago, Illinois, USA were included in this cross-sectional, convergent mixed methods study conducted between May and October of 2022. English-speaking patients, aged 18 and older, were eligible if they had a diagnosis of migraine in their electronic health records (EHR) and had attended at least one visit with a neurology provider during the 6 months prior to enrollment. Potential participants were identified by an EHR query. These individuals were mailed letters informing them of the study and providing them with an option to 'opt out' of further contact from the study team. A research coordinator phoned those who did not opt out, screened them for eligibility, and engaged them in the informed consent process.

Neurologists were eligible if they were currently practicing at a neurology clinic affiliated with the participating health center. They were recruited via an email to the neurology practice listserv and asked to contact the study team if they were interested in participating. Those who contacted the team were screened and engaged in the informed consent process.

### 2.2. Data collection

Enrolled patient participants were administered a structured survey by trained research coordinators over a secure videoconferencing platform. Surveys took approximately 45 min to complete. Participants self-reported sociodemographic characteristics, including sex, age, income, education, and health insurance. Other self-reported characteristics included race and ethnicity, though we recognize these are US-centric; our purpose was to recruit a sample reflective of the patient population with migraine in the US where the condition is known to affect White women more than other groups. Participants also provided their age at onset of migraine symptoms and diagnosis. Additional measures captured included: health literacy; MOH awareness and knowledge; and perceptions of patient-provider communication. Health literacy was assessed using the validated Health Literacy-6 scale (HL6), completed immediately following the interview via text messaging (Bailey et al., 2023). To assess MOH knowledge, participants were asked: 1) whether medications used to treat headaches can also cause headaches (true/false), 2) whether certain medications (e.g. combination pain relievers, acetaminophen, aspirin) can cause MOH (yes/no, per medication type; all needed to be answered correctly to receive credit), and 3) how often over-the-counter medications can be taken to avoid MOH (every time you have a headache vs. two times per week or less). Scores were summed 0–3 with higher scores indicating greater MOH knowledge. Patient-provider communication was assessed using a modified set of questions from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Provider Communication subscale. As in prior studies, responses to CAHPS questions were dichotomized as 'definitely' vs. 'somewhat' or 'no' (Singleton et al., 2022). Finally, open ended questions solicited information on what, if anything, providers had told participants about MOH.

Neurologists completed individual, in-depth interviews conducted

remotely over videoconferencing software. Interviews were targeted and brief, lasting up to 30 min. Research coordinators used an interview guide seeking to uncover: 1) when initial communication about MOH occurs; 2) how MOH is typically described to patients, and 3) MOH communication needs. At the conclusion of each interview, providers completed a brief survey capturing sociodemographic and professional characteristics. All interviews were audio recorded and research coordinators took detailed memos at the conclusion of each.

### 2.3. Ethical approval

Ethical approval for study activities was provided by Northwestern University's Institutional Review Board which provides protections for human subjects' safety and privacy. All study participants provided informed consent prior to participating, and all were compensated for their time.

### 2.4. Analysis

Quantitative data from patient participants was analyzed using descriptive statistics for variables measuring sociodemographic characteristics and information pertaining to the age of migraine symptom onset and diagnosis. Awareness and knowledge of MOH, as well as the quality of patient-provider communication, were also analyzed using descriptive statistics. Bivariate analyses utilizing the Shapiro-Wilk and Mann Whitney tests examined differences between patient-provider communication and MOH knowledge scores. SAS software (Cary, NC) was used to conduct all quantitative analyses.

Qualitative analysis of data collected from interviews with neurologists, was conducted using a modified version of the Rapid Identification of Audio Recordings (RITA) procedures (Neal et al., 2015). RITA is a largely deductive approach to thematic analysis; however, we supplemented *a priori* codes based on our interview guide with *emergent* codes revealed during memo-writing (Tolley et al., 2016). We then created a matrix with rows representing individual participants and columns representing separate codes. Two coders listened to the audio files and populated the matrix. The first two interviews were double coded, and the codebook refined; the remaining interviews were coded separately. Coders reviewed memos and discussed findings to ensure trustworthiness (Tolley et al., 2016). Once coding was complete, summaries were written for each code across participants, revealing overall themes. Illustrative quotes were identified and transcribed (Tolley et al., 2016).

After completing separate analyses of the survey and interviews, we integrated data using a side-by-side joint display, common for convergent mixed methods studies (Creswell, 2018). This provided an understanding of MOH communication from the perspective of both parties.

## 3. Results

### 3.1. Participant characteristics

Patient characteristics are presented in Table 1. This sample included a total of 200 patients whose characteristics largely reflect individuals diagnosed with migraine in the US. Most were female (82.9%), and the average age was 43 years (Table 1). Just over half (57.4%) self-identified as White, 15.9% as Hispanic and 14.9% as Black. Nearly a third (31.8%) had annual household incomes less than \$50,000. The HL6 assessment revealed almost 1 in 5 (18.2%) had limited health literacy.

Of the 30 neurologists who were sent a recruitment email about the study, 14 expressed interest, and 13 were consented, enrolled and interviewed. This sample size is considered sufficient for thematic saturation (Hennink and Kaiser, 2022; Guest and Johnson, 2006). Those who participated were diverse by sex (n = 8 female, n = 7 male); 8 were neurology residents or had completed residency in the past 5 years. The remaining had at least 11 years of experience post-residency.

**Table 1**  
Distribution of Participant Characteristics Collected in 2022 Among Adult Migraine Patients Attending an Academic Health Center in the Midwest of the United States.

	Overall (N = 200)
Sex <sup>a</sup> , n (%)	
Male	34(17.1)
Female	165(82.9)
Age	
Mean (SD)	43.08(15.3)
Age category, n (%)	
18–30	45(22.5)
31–50	91(45.5)
>50	64(32.0)
Race and ethnicity <sup>b</sup> , n (%)	
Hispanic or Latinx	31(15.9)
Black or African American	29(14.9)
White or Caucasian	112(57.4)
Other	23(11.8)
Education, n (%)	
Some college or less	70(35.0)
College graduate	64(32.0)
Graduate degree or more	66(33.0)
Insurance <sup>c</sup> , n (%)	
Private	131(66.2)
Medicaid	25(12.6)
Medicare	20(10.1)
Multiple	18(9.1)
Other	4(2.0)
Income <sup>d</sup> , n (%)	
Less than \$50,000	57(31.8)
Between \$50,000 and \$99,999	44(24.6)
\$100,000 or more	78(43.6)
Health literacy <sup>e</sup> , n (%)	
Limited	34(18.2)
Adequate	153(81.8)

<sup>a</sup> 1 missing, <sup>b</sup>5 missing, <sup>c</sup>2 missing, <sup>d</sup>21 missing, <sup>e</sup>13 missing.

3.2. Mixed methods findings

Mixed methods findings are presented in Table 2. We organized results around our three questions: 1) When does initial patient-provider communication about MOH occur?; 2) How is MOH described to patients?; and 3) What are current MOH communication needs? Under each question, we present the patient data, followed by the neurologist data. In keeping with our study design, a brief integration, combining the two types of data, provides an overarching response to each question (Creswell, 2018).

1. When does initial patient-provider communication about MOH occur?

3.2.1. 3.2.1 Patient data

Over a third (39.5 %) of migraine patients reported they had never heard of ‘medication overuse headache.’ Of those who were familiar, about half (53.4 %) said they had discussed it with their current neurologist, while 50 % said they had discussed it with another provider (options were not mutually exclusive). Among patients who had discussed MOH with their current neurologist or other provider, there was variability in when they first learned about MOH from a provider: 15.1 % learned at the time of migraine diagnosis, 24.4 % within the first year of diagnosis, 19.8 % from 1 to 5 years after diagnosis, and 38.4 % learned more than 5 years after migraine diagnosis. A small percentage (2.3 %) reported their provider had not discussed MOH with them.

3.2.2. 3.2.2 Neurologist data

All neurologists indicated patients rarely, if ever, bring up medication overuse headache with them.

**Table 2**  
Side-by-Side Comparison of Mixed Methods Findings Collected in 2022 from Adult Patient Participants and Neurologists at an Academic Health Center in the Midwest of the United States.

Thematic Question	Quantitative and Open-Ended Survey Results with Patients	Qualitative Interview Results with Neurologists	Mixed Methods Interpretation
When does initial patient-provider communication about MOH occur?	Over a third (39.5 %) of migraine patients (N = 200) had never heard of MOH. Among those who had, over a third (38.4 %) learned more than 5 years after migraine diagnosis.	All neurologists (N = 13) indicated patients rarely, if ever, initiate conversations about MOH. Instead, conversations are driven by neurologists as a result of patient reported behaviors or symptoms.	Initial patient-provider communication about MOH is often delayed and reactive.
How is MOH typically described to patients?	Among patients who responded to open-ended questions (N = 63), over half (59 %) revealed their neurologists or other providers had described MOH to them as a result of taking relief medication too frequently.	Nearly all neurologists noted they describe MOH as a consequence of frequent medication-taking. Nevertheless, the terms they use to refer to MOH vary, with some neurologists choosing terms they feel are more easily understood or less likely to stigmatize the condition.	The concept of MOH is consistently described as a consequence of frequent medication taking, though specific terminology varies.
What are current MOH communication needs?	Although patients viewed communication with their neurologists favorably, perceptions were not associated with MOH knowledge.	Neurologists indicated they would like education and tools to encourage earlier communication about MOH.	Communication about MOH does not currently result in improved MOH knowledge, but tangible education materials, delivered early to migraine patients, may help.

“[Patients] pretty much never [bring it up] ... It’s not as commonly known that medications can cause headaches... I don’t think it’s commonly told to people.” (Female neurologist)

Neurologists also reported that although they assess patients for MOH at the initial visit and during migraine diagnosis, they typically wait to initiate conversations until behaviors or symptoms suggest the condition may be a concern. Approximately half of the neurologists reported frequent medication use and/or refill requests are the behaviors most often alerting them to possible medication overuse and prompting discussions.

“If I find that they are using an NSAID, Tylenol or what have you - something that increases the likelihood of medication overuse - then I’ll ask how often they are taking it. And if I find that they are taking something more than 3 times per week - then, at that time, I’ll broach the topic of MOH.” (Male neurologist)

Several others noted they are typically concerned about the potential for MOH when a patient describes having daily, chronic headaches. As with behaviors, neurologists noted these symptoms are likely to prompt

discussions about MOH.

*“I think that’s the main one [symptom] that they’re presenting with – headache that’s either constant or goes away and comes back each day, or even later in the day when they take something and then they need to take something again for it.” (Male neurologist)*

3.2.3. 3.2.3 Mixed methods integration

Taken together, patient and neurologist data suggest initial patient-provider communication about MOH is often delayed and reactive.

2. How is MOH typically described to patients?

3.2.4. 3.2.4 Patient data

Most patients (n = 37, 59 %) who responded to open-ended questions about how their providers had described MOH to them reported being told that the use or overuse of certain medications can lead to additional headache problems including aggravating existing headaches or causing continuous headaches, ‘rebound headaches’, or ‘other migraines’. For example, one patient noted:

*“Basically [the neurologist told me] that sometimes the relief medication can cause rebound headaches, so you have to be careful with how frequently you take them.” (Female patient)*

3.2.5. 3.2.5 Neurologist data

Nearly all neurologists indicated they describe medication overuse headache as a ‘consequence’ of the patient’s frequent medication taking. Neurologists often explained medication overuse as making the headaches ‘worse’ or ‘more frequent’. For example, one neurologist recounted:

*“[I say] I’m concerned that you’re taking medication to stop the headache at a frequency such that while it can help in the short term, it’ll actually make the headache worse in the long term – that you’re likely to have ‘rebound’.” (Male neurologist)*

Neurologists were largely split on the terms they typically use with patients. Several noted they often use the term ‘rebound headache’, while a similar number reported a preference for ‘medication overuse headache’. Two neurologists noted they use both terms together. When asked why they used the terms they do, neurologists noted they perceive their preferred term to be easier for patients to understand and/or less stigmatizing.

*“I use [rebound headache] because it makes it easier to understand ... Medication overuse can be more judgmental and stigmatized in the context of any sort of prescription pain medication.” (Male neurologist)*

Despite expressing some concern about whether specific terms are perceived as stigmatizing to patients, most neurologists thought patients do not find the concept of MOH to be stigmatizing.

*“Stigmatizing? I would say no... if people are taking Advil, which is available over-the-counter, they’re not usually stigmatized cause they think they’re just doing what the bottle says.” (Female neurologist)*

3.2.6. 3.2.6 Mixed methods integration

While the concept of MOH is consistently described, specific terminology varies, largely depending on the extent to which neurologists find the terms to be understandable and/or stigmatizing to patients.

3. What are current MOH communication needs?

3.2.7. 3.2.7 Patient data

Patients were asked about their satisfaction with the neurologist they most recently saw, and the quality of the conversations they had with that provider. Generally, patients reported high levels of satisfaction

with the last neurologist they saw, with an average rating of 8.8 on a scale of 1 to 10 (with 10 being best). Most participants (69.5 %) reported their latest visit in neurology was with a provider they had seen previously. Most also reported their neurologist ‘definitely’ explained things in a way that was easy to understand (80.5 %), listened carefully to them (86.5 %), showed respect for what they had to say (92.5 %), spent enough time with them (86.5 %), and had the medical information they needed about them (79.5 %). In bivariate analyses, no significant differences were found between patient knowledge of MOH and patient reported perceptions of provider communication (measured using CAHPS) (Table 3).

3.2.8. 3.2.8 Neurologist data

A couple of neurologists perceived patient understanding of MOH may be dependent on the amount of time neurologists take to explain the concept, suggesting they need dedicated time to discuss MOH with patients.

*“The patients that we take time to spend with and talk about medication overuse headaches will have generally a better understanding of what it is and why they should avoid medications.” (Female neurologist)*

Most neurologists noted when they do discuss MOH with patients, they generally assess understanding by asking questions and using ‘teach back’.

*“With patients for whom I’m concerned there’s understanding issues, I’ll ask if they have questions or concerns and have them explain how often they can take the rescue medicine.” (Female neurologist)*

Unprompted, some neurologists revealed when they informed patients about MOH, their patients seemed surprised they had not been previously told about the condition, or that the medications they were taking to prevent headaches were causing worse or additional headaches.

*“In fact, many of them are surprised that nobody had told them before that this could also happen.” (Female neurologist)*

When asked what resources they thought would be useful to their practice, most neurologists noted they would like to have education materials on MOH they can share early with patients. A couple neurologists requested materials be standardized and readily available in the EHR as after-visit summaries.

*“It would be helpful to have one of the attached after-visit summaries about medication overuse headaches... It’s easier for patients if it’s*

**Table 3**  
Bivariate Relationship Between Patient Knowledge of Medication Overuse Headache and Patient Reported Perceptions about Provider Communication: Data Collected in 2022 from Adult Patient Participants Attending an Academic Health Center in the Midwest of the United States.

	Among patients seeing their usual provider (N = 139)	Definitely	Somewhat/No	P-value
		mean (SD)	mean (SD)	
Explain things easy to understand		2.1(0.8)	2.0(1.0)	0.7
Listen carefully to you		2.1(0.8)	1.9(0.9)	0.3
Show respect for what you had to say		2.1(0.8)	2.1(1.1)	0.7
Spend enough time with you		2.1(0.8)	2.3(0.7)	0.1
Have the medical information they needed about you		2.1(0.8)	2.2(0.9)	0.3
Among all patients (N = 200)				
Explain things easy to understand		2.1(0.8)	1.9(1.1)	0.5
Listen carefully to you		2.1(0.8)	1.8(1.0)	0.2
Show respect for what you had to say		2.1(0.8)	2.3(1.0)	0.2
Spend enough time with you		2.0(0.9)	2.3(0.9)	0.1
Have the medical information they needed about you		2.0(0.9)	2.2(0.9)	0.3

\*SD: Standard deviation.

written down and they can read it on their own time.” (Female neurologist)

Similarly, a couple of neurologists thought information on support groups would also be helpful information to add for patients.

### 3.2.9. 3.2.9 Mixed methods integration

Communication about MOH does not currently result in improved patient MOH knowledge, but supportive education materials are desired.

## 4. Discussion

We conducted a mixed methods study with migraine patients and neurologists at a large academic health center located in and around Chicago, Illinois to better understand patient-provider communication and information needs specific to MOH. Findings reveal key opportunities for improving patient-provider communication about MOH.

In quantitative surveys, many patients reported limited and delayed awareness of MOH relative to migraine symptom onset and diagnosis. This finding was supported by qualitative interview data from neurologists, half of whom revealed they typically wait to discuss MOH with patients until they present with a behavior and/or symptom indicative of the condition. Separately, some neurologists reflected that when patients first learn about medication overuse headache, they often seem surprised no one had informed them about it earlier. The delayed and reactive nature of these discussions, nearly always prompted by a neurologist, and the perception that patients would like to learn about the condition well before they experience worse or additional pain, suggests a need for earlier, preventive education. In Denmark, a national MOH campaign was implemented and successfully increased awareness of MOH among the public and galvanized interest in the condition (Carlsen et al., 2018; Munksgaard et al., 2011). We are unaware of efforts in the US, either publicly or within healthcare settings, that have been implemented to increase MOH awareness prior to diagnosis.

Our findings also revealed nearly all neurologists described the condition as a ‘consequence’ of frequent medication-taking; this was supported by over half of patients responding to open-ended questions. Despite this consistency, neurologists reported using a variety of terms, including ‘rebound headache’, explaining their choices hinged on perceived patient understandability and/or potential stigmatization. Although scientific literature notes these terms can be used interchangeably, future research should explore how patients perceive the terms, and the extent to which they find them stigmatizing (Fischer and Jan, 2024). Studies conducted among individuals with varying other health conditions have found stigma to be substantial barrier to necessary healthcare access and use, negatively affecting individual health outcomes (Graham et al., 2022; Nawfal et al., 2024; Zhou et al., 2022).

We found no association between quality of patient-provider communication and MOH knowledge. While previous randomized trials examining the effect of patient education on the management of MOH in Europe and Latin America have shown modest benefits (Mose et al., 2021; Tassorelli et al., 2017; Grande et al., 2011; Kristoffersen et al., 2016; Pijpers et al., 2022), additional studies are needed to examine whether patient education and/or quality patient-provider communication can prevent MOH. This is important as some neurologists in our study expressed a desire for written, plain language, patient education materials on MOH which could be easily integrated into after-visit summaries. Ideally this written education would complement provider counseling, as prior studies with migraine patients have revealed a preference for collaborative patient-provider relationships (Cottrell et al., 2002). Education should also be designed to counter patient misconceptions and beliefs about MOH (Jonsson et al., 2013; Frich et al., 2014). Our team has successfully created low literacy health education materials designed for use within the EHR for other health conditions (Bailey et al., 2019; Light et al., 2023; Pack et al., 2023; Pack

et al., 2023). While similar patient education on MOH would be beneficial in a neurology setting, many patients with migraine are seen first in primary care and are only referred to neurology after symptoms progress. We argue that the delivery of patient education is needed in primary care to potentially prevent MOH. Such education may need behavioral support to ensure medication is taken at safe and appropriate frequencies and amounts between clinic visits.

Our study has limitations that should be considered. First, participants were recruited using convenience sampling. Those who chose to participate may have different views than those who chose not to. Participants were also recruited from a single academic health center; as such, results may not be generalizable. Furthermore, we are unable to make any inferences into causality as the study was cross-sectional.

## 5. Conclusions

In conclusion, findings indicate limited awareness of MOH among patients with migraine. Neurologists are likely to discuss MOH with patients in response to a behavior or symptom indicating medication overuse may already be occurring. Future research should explore the content, and ideal setting for preventive education on MOH. This includes assessing whether education should occur in primary care where many patients initially seek care for migraine symptoms.

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## CRedit authorship contribution statement

**Allison Pack:** Writing – original draft, Methodology, Formal analysis. **Rachel O’Conor:** Writing – review & editing, Methodology. **Yvonne Curran:** Writing – review & editing, Supervision. **Wei Huang:** Writing – review & editing, Formal analysis. **Andrea Zuleta:** Writing – review & editing, Project administration. **Rodolfo Zuleta:** Writing – review & editing, Investigation, Formal analysis. **Melissa P. Herman:** Writing – review & editing, Conceptualization. **Steven M. Kymes:** Conceptualization. **Stacy C. Bailey:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization.

## Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr. Pack reports grants from Merck, Pfizer, Gilead, Gordon and Betty Moore Foundation, RRF Foundation for Aging, Lundbeck, and Eli Lilly through her institution, and personal fees from Gilead. Dr. Bailey reports grants from the NIH, Gilead, Merck, Pfizer, Gordon and Betty Moore Foundation, RRF Foundation for Aging, Lundbeck, and Eli Lilly via her institution and personal fees from Gilead, Sanofi, Pfizer, University of Westminster, Lundbeck, and Luto UK outside the submitted work. Ms. Herman is employed full time by Lundbeck and Dr. Kymes was employed full time by Lundbeck at the time of the research.

## Data availability

Data will be made available on request.

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