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**Headache: The Journal of Head and Face Pain**

DOI:

[10.1111/head.14430](https://doi.org/10.1111/head.14430)

Published: 01/02/2023

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*

Urtecho, M., Wagner, B., Wang, Z., VanderPluym, J., Halker Singh, R. B., Noyes, J., Butler, M. E., & Murad, M. H. (2023). A qualitative evidence synthesis of patient perspectives on migraine treatment features and outcomes. *Headache: The Journal of Head and Face Pain*, 63(2), 185-201. <https://doi.org/10.1111/head.14430>

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## REVIEW ARTICLE

# A qualitative evidence synthesis of patient perspectives on migraine treatment features and outcomes

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## Funding information

Agency for Healthcare Research and Quality, Grant/Award Number: HHSA 290 2015 00008I, HHSA 290 2015 00013I and HHSA 290-2017-00003C

## Abstract

**Objectives:** We aimed to identify migraine treatment features preferred by patients and treatment outcomes most valued by patients.

**Background:** The values and preferences of people living with migraine are critical for both the choice of acute therapy and management approach of migraine.

**Methods:** We conducted a qualitative evidence synthesis. Two reviewers independently selected studies, appraised methodological quality, and undertook a framework synthesis. We developed summary of findings tables following the approach of Grading of Recommendations, Assessment, Development and Evaluations Confidence in the Evidence from Reviews of Qualitative Research to assess confidence in the findings.

**Results:** Of 1691 candidate references, we included 19 studies (21 publications) involving 459 patients. The studies mostly recruited White women from North America (11 studies) and Europe (8 studies). We identified eight themes encompassing features preferred by patients in a migraine treatment process. Themes described a treatment process that included shared decision-making, a tailored approach, trust in health-care professionals, sharing of knowledge and diversity of treatment options, a holistic approach that does not just address the headache, ease of communication especially for complex treatments, a non-undermining approach, and reciprocity with mutual respect between patient and provider. In terms of the treatment itself, seven themes emerged including patients' preferences for nonpharmacologic treatment, high effectiveness, rapidity of action, long-lasting effect, lower cost and more accessibility, self-management/self-delivery option that increases autonomy, and a mixed preference for abortive versus prophylactic treatments. The treatment outcomes that have high value to patients included maintaining or improving function; avoiding side effects, potential for addiction to medications, and pain reoccurrence; and avoiding non-headache symptoms such as nausea, vomiting, and sensitivity to light or sounds.

**Abbreviations:** AHRQ, Agency for Healthcare Research and Quality; CASP, Critical Appraisal Skills Programme; CERQual, Confidence in the Evidence from Reviews of Qualitative Research; ED, emergency department; GRADE, Grading of Recommendations, Assessment, Development and Evaluations; IV, intravenous; PRO, patient-reported outcome; SDM, shared decision-making.

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**Conclusion:** Patient values and preferences were individually constructed, varied widely, and could be at odds with conventional medical perspectives and evidence of treatment effects. Considering the availability of numerous treatments for acute migraine, it is necessary that decision-making incorporates patient values and preferences identified in qualitative research. The findings of this qualitative synthesis can be used to facilitate an individually tailored approach, strengthen the patient–health-care system relationship, and guide choices and decisions in the context of a clinical encounter or a clinical practice guideline.

#### KEYWORDS

migraine, patients' preferences, qualitative synthesis, treatment

## INTRODUCTION

Migraine is a very common condition that can be associated with significant morbidity.<sup>1</sup> To assess the effectiveness of acute treatment of migraine attacks, clinical trials usually evaluate being pain free, pain relief, and functionality.<sup>2</sup> Interventions such as triptans, non-steroidal anti-inflammatory drugs, acetaminophen, dihydroergotamine, calcitonin gene-related peptide antagonists, lasmiditan, and some non-pharmacologic treatments are associated with improved pain and function.<sup>3,4</sup> These treatments in general have transient and mild adverse events that may vary in their acceptability to patients.<sup>3</sup> There are also many options for preventive treatment of migraine.<sup>5,6</sup> After considering medical comorbidities that may preclude the use of certain treatments, the choice of therapy heavily depends on patient values and preferences. Knowledge of these values and preferences is important for decision-making in the context of guideline development, and in clinical encounters between patients and health-care professionals.

Values and preferences are overarching terms that include patient perspectives, beliefs, expectations, and goals for health and life.<sup>7</sup> In the decision-making framework Grading of Recommendations, Assessment, Development and Evaluations (GRADE), the term "value" is operationalized as the way patients assess the desirable and undesirable effects of a management approach, akin to utilities and disutilities, whereas preferences can refer to specific partialities for treatment features. Variability or uncertainty about values and preferences can lower the confidence of decision makers.<sup>8</sup>

Therefore, we aimed to synthesize qualitative studies that identified acute migraine treatment features preferred by patients and the migraine treatment outcomes that patients valued. The effectiveness of treatments was not the focus, but rather the patient perspective and experience regarding treatments and their outcomes.

## METHODS

Two key questions were developed using PerSPECTiF, a framework used to explore phenomena, perspectives, and complex interventions in qualitative evidence synthesis<sup>9</sup> (Table 1).

*Key question 1:* What treatment features do people living with migraine prefer? (e.g., access, cost, knowledge, attitudes, confidence, route of administration, speed of action, efficacy, tolerability, etc.).

*Key question 2:* What treatment outcomes are preferred or important to people living with migraine? (e.g., quality of life; satisfaction; reduction in pain; resolution of pain; time to pain resolution; non-headache symptoms such as nausea, vomiting, photophobia; side effects; etc.).

## Search strategy and study selection process

A search algorithm was developed and run for MEDLINE using Medical Subject Headings or key words for migraine and treatment concepts, with a filter to identify qualitative research (see supporting information). The search was then modified for Embase and CINAHL databases. We used key words such as "migraine," "semi-structured," "qualitative," "interview." All searches were run from inception through December 2020. References were uploaded to Distiller,<sup>10</sup> where duplicates were removed. Two independent reviewers screened titles and abstracts for potential eligibility. Inclusion was confirmed by two independent reviewers using full text. Disagreements were resolved by consensus, using a third reviewer if necessary. Regular meetings were held during screening to assure calibration across reviewers. Inclusion and exclusion criteria are summarized in Table S1 in supporting information.

## Quality assessment

We assessed the methodological quality of included studies using the Critical Appraisal Skills Programme (CASP) quality appraisal tool for qualitative research.<sup>11</sup> One reviewer extracted the data and conducted the assessment and a second reviewer verified data. Disagreements were resolved by discussion between reviewers. CASP appraisal also assisted in determining the applicability of individual study findings to the overarching themes identified in synthesis.

TABLE 1 Systematic review questions according to the PerSPECTiF framework.

Perspective (Per)	Setting (S)	Phenomenon of interest (P)	Environment (E)	Comparison (C)	Timing (Ti)	Findings (F)
Adults (≥18 years) living with migraine	Any settings	<p><i>Key question 1:</i> Migraine treatment features preferred by patients from patients' perspective</p> <p><i>Key question 2:</i> Migraine treatment outcomes important to patients from patients' perspective</p>	Any	<p>Patient perspectives and experiences of different treatments</p> <p>None</p>	No limits	<p>Access, cost, knowledge, attitudes, confidence, route of administration, speed of action, efficacy, tolerability, etc.</p> <p>Quality of life; satisfaction; reduction in pain; resolution of pain; time to pain resolution; non-headache symptoms such as nausea, vomiting, photophobia; side effects; etc.</p>

## Data extraction and synthesis

Initial data extraction using a standardized spreadsheet template captured basic study characteristics. We followed a five-stage framework synthesis approach in which findings were interrogated, discussed, mapped, charted, and refined. To frame our questions, we adapted the preliminary framework from the original analytic model employed in a related systematic review of acute treatments for migraine<sup>3,4</sup> by incorporating shared decision-making (SDM) and health-behavior models<sup>12,13</sup> (Figure S1 in supporting information). We extracted first-order (direct participant quotes) and second-order (interpretations of primary study authors) constructs and assigned coding from the included studies. Each reviewer extracted data and coded according to framework themes in terms of people with migraines' experience of the features and outcomes as positive or negative. The team reviewed findings considering quality assessment and applicability (CASP) to inform suitability for including individual study findings in overarching themes. One author then synthesized the coded data into overarching themes driven by our framework, although finer grained elements from the data were also retained. A second author developed the overarching themes into findings statements that were reviewed by all team members for accuracy and comprehensiveness. Data coding was compared and discussed for each publication. During this step, we found that the coded themes either directly informed the two key questions or were contextual factors that mitigated or mediated how patients valued outcomes or expressed preferences for treatment features. We noted where our adapted framework expanded relevant literature to include studies describing people with chronic and episodic migraine, in addition to people with acute migraine attacks. Findings are reported according to the Enhancing Transparency in the Reporting the Synthesis of Qualitative Research (ENTREQ) tool, which promotes explicit and comprehensive reporting of the synthesis of qualitative studies.<sup>14</sup>

## Assessment of confidence in synthesized findings

We used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative Research) approach to assess confidence in

the findings derived from the qualitative evidence.<sup>15</sup> This approach evaluates the methodological limitations of the contributing studies (e.g., data collection procedures and synthesis methods), and the coherence, adequacy, and relevance of the extracted data to the review finding. The process of rating followed the GRADE-CERQual series published by each component.<sup>16-19</sup> Overall confidence can be rated as high, moderate, low, or very low. Initial assessment was conducted by one reviewer and finalized by team discussion and consensus.

## Author reflexivity and patient involvement

Our researcher team has wide experience with systematic reviews, evidence synthesis, and migraine, and some authors with qualitative research and qualitative evidence synthesis. Bias among our team member is possible because we have previously published a systematic review assessing treatments for the management of acute migraine.<sup>3</sup> A virtual meeting was scheduled every week to discuss and assess study progress, reconcile differences and disagreements, and decrease and mitigate potential biases we may have held.

Three patients with a history of migraine provided feedback on the identified themes, synthesis, and conclusions. The selection of these patients followed a convenience sampling approach in that they were recruited by the clinicians on our team. This selection may also reduce the internal and external validity of their input. The patients emphasized that the treatment process should avoid undermining the disease burden of migraine that patients encountered often when interacting with health-care providers. They highlighted the need for treatment processes that provide education to patients about the pathophysiology of migraine and how pharmacologic and non-pharmacologic treatments work; as well as provider education about validating patients' experiences and taking into consideration the patients' preferred treatment.

This research is based on work conducted by the Agency for Healthcare Research and Quality (AHRQ) Evidence-Based Practice Centers at the Mayo Clinic and University of Minnesota. AHRQ did not directly participate in the literature search, design, and conduct of the study; collection, management, analysis, and interpretation

of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

## FINDINGS

The study selection process is depicted in Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 1). The search strategy yielded 1691 references. We ultimately included 19 studies from 21 publications reporting on 459 patients. Three publications<sup>20–22</sup> shared the same cohort of participants and thus were counted as one study. We contacted the authors of Rutberg et al. and verified that their three studies had unique patients.<sup>23–25</sup> The studies mostly included White women from North America (eleven studies) and Europe (eight studies). Only two studies explicitly reported on Black or Hispanic/Latino populations.<sup>26,27</sup> Grounded theory and content analysis were the main methodologies used by the primary studies. Most of the studies collected data using semi-structure interviews, and four studies conducted focus groups. We included studies that focused on acute treatment of migraine attacks, with the exception of one study that focused on prophylactic treatment but addressed some aspects of acute treatments.<sup>28</sup> The characteristics of included studies are summarized in Table S2 in supporting information.

Methodological quality assessment using the CASP applicability tool is detailed in Table S3 in supporting information.

### Key question 1 (patient preferences for treatment features)

#### Preferences about the treatment process

We identified eight overlapping themes preferred by patients in a migraine treatment process: (1) shared decision-making, (2) a

tailored approach, (3) trust in health-care professionals, (4) inclusion of knowledge and options, (5) a holistic approach, (6) ease of communication, (7) a non-undermining process, (8) a process that includes reciprocity. The latter two features were described with a negative valence (i.e., features not desired in a process, undermining, and lack of reciprocity).

Statements that summarize these findings and the confidence in synthesized findings are reported in Table 2. Supportive quotes are presented in Table S4 in supporting information. Additional details and description of the themes are presented in Appendix 1.

#### Preferences about the treatment itself

The seven themes that related to preferences about the features of the treatment itself were inclination for: (1) nonpharmacologic treatment, (2) high effectiveness, (3) rapidity of action, (4) long-lasting effect, (5) lower cost and more accessibility, (6) abortive and prophylactic treatment, without clear preference between the two, and (7) self-management/self-delivery option. Statements that summarize these findings and the confidence in synthesized findings are reported in Table 3. Supportive quotes are presented in Table S5 in supporting information. Additional details and description of the themes are presented in Appendix 2.

### Key question 2 (outcomes valued by patients)

Thirteen of the included studies reported on how migraine treatment outcomes were valued by patients. We identified five themes that had high value to patients: (1) side effects, (2) potential for addiction to medications, (3) function, (4) pain reoccurrence, (5) non-headache symptoms. Statements that summarize these findings and the confidence in synthesized findings are reported in Table 4.

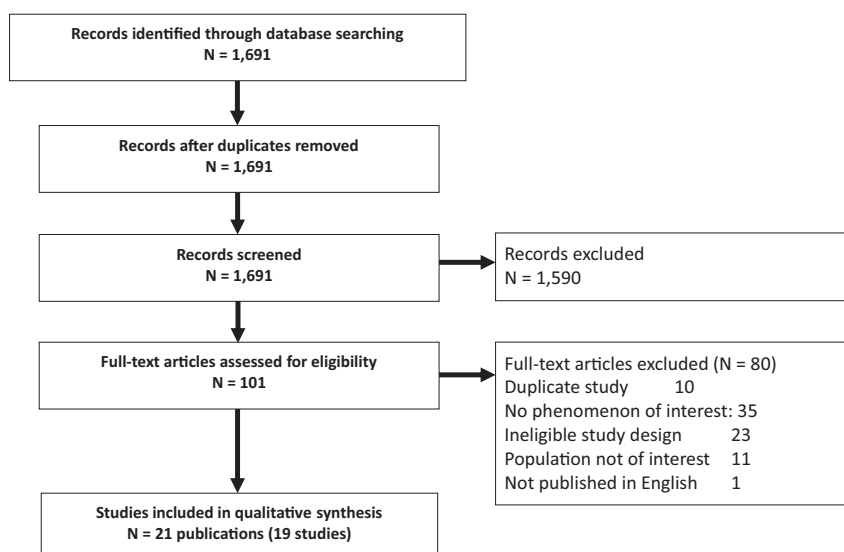


FIGURE 1 The process of study selection.

TABLE 2 Summary of findings: Preferences about the treatment process.

Treatment process features (number of studies)	Findings statements	Studies	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Shared decision-making (4 studies)	Patients prefer processes that ensure they receive explanations of their health and treatment options, are active participants in their care, and share decision-making with the clinician	Befus (2019), Belam (2005), Connor (2021), Rutberg (2013) <sup>25,26,29,30</sup>	High confidence	One study with major concerns (Befus 2019), and three studies with minor concerns (Belam 2005, Connor 2021, Rutberg 2013). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Tailored approach (4 studies)	Patients prefer treatment processes that are tailored to their individual experience(s), treatment choices, conditions, and circumstances	Befus (2019), Connor (2021), Morgan (2015), Rutberg (2013) <sup>25,26,29,31</sup>	High confidence	One study with major concerns (Befus 2019), and three studies with minor concerns (Connor 2021, Rutberg 2013, Morgan 2016). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Trust in health-care professional (5 studies)	Patients prefer treatment processes that feature trust in the clinician. Trust allows patients and clinicians to notice and share information vital to treatment decisions	Belam (2005), Connor (2021), Dekker (2012), Khan (2015), Rutberg (2013) <sup>25,28-30,32</sup>	High confidence	Three studies with minor concerns (Belam 2005, Connor 2021, Rutberg 2012) and two studies with no concerns (Dekker 2012, Khan 2015). Minor concerns regarding methodological limitations and coherence. There were no concerns regarding relevance and adequacy
Provides knowledge about treatment & options (8 studies)	Patients prefer treatment processes in which knowledge is conveyed to patients about the condition and treatment options	Befus (2019), Belam (2005), Connor (2021), Dekker (2012), Huddleston (2018), Morgan (2015), Peters (2003), Rutberg (2013) <sup>20,25-31</sup>	High confidence	One study with major concerns (Befus 2019), five studies with minor concerns (Belam 2005, Connor 2021, Huddleston 2018, Morgan 2016, Rutberg 2013), a sibling study with minor concern (Peters 2003), and one study with no concern (Dekker 2012). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Holistic approach (2 studies)	Patients prefer treatment processes that engage them in a learning conversation as whole persons, rather than processes that merely attend to the headache	Befus (2019), Connor (2021) <sup>26,29</sup>	Moderate confidence	One study with major concerns (Befus 2019), and one study with minor concerns (Connor 2021). Major concerns regarding methodological limitations (body of evidence is small). Minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Ease of communication (5 studies)	Patients prefer treatment processes that include easy communication with the health-care team, especially for complex treatments for migraine such as behavioral interventions and self-administered techniques	Connor (2021), Dekker (2012), Huddleston (2018), Morgan (2015), Rutberg (2013) <sup>25,27-29,31</sup>	High confidence	Four studies with minor concerns (Connor 2021, Huddleston 2018, Morgan 2016, Rutberg 2013), and one study with no concerns (Dekker 2012). Minor concerns regarding coherence. There were no concerns regarding methodological limitations, relevance, and adequacy

(Continues)



TABLE 2 (Continued)

Treatment process features (number of studies)	Findings statements	Studies	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
<i>Undermining (5 studies)</i>	Patients prefer processes that do not undermine the legitimacy of the patient's own experience, preferences, and ability to participate in their care and treatment decisions	Befus (2019), Connor (2021), Dekker (2012), Khan (2015), Palacios-Cena (2017) <sup>26,28,29,32,33</sup>	High confidence	One study with major concerns (Befus 2019), two studies with minor concerns (Connor 2021, Palacios Cena 2017), two with no concerns (Dekker 2012, Khan 2015). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
<i>Lack of reciprocity (5 studies)</i>	Patients prefer reciprocal treatment processes where mutual respect can be exercised between patient and provider	Befus (2019), Belam (2005), Cottrell (2002), Palacios-Cena (2017), Rutberg (2013) <sup>25,26,30,33,34</sup>	High confidence	One study with major concerns (Befus 2019), and four studies with minor concerns (Belam 2005, Cottrell 2002, Palacios Cena 2017, Rutberg 2013). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy

Abbreviation: CERQual, Confidence in the Evidence from Reviews of Qualitative Research.

Supportive quotes are presented in [Table S6](#) in supporting information. Additional details and description of the themes are presented in [Appendix 3](#).

The themes identified in this evidence synthesis, associated confidence level in each theme statement, and the number of supporting studies per theme are depicted in [Figure 2](#).

## DISCUSSION

We conducted a qualitative evidence synthesis to identify migraine treatment features preferred by patients and the treatment outcomes that patients valued. Patients' preferences started with a solid and trusting relationship with health-care providers that involved individualized therapy and shared decision-making as cornerstones for a successful treatment. Patients felt that treatment of migraine was more than just a prescription but rather a shared experience of understanding and education between the clinician and the patient. One highlighted feature was the importance of non-pharmacological treatments. Patients expressed strong preference for health-care professionals with more knowledge about non-pharmacological treatments and a desire for a wider availability of these treatments.

Findings highlight the complex and nuanced nature of migraine treatment. People living with migraine described their struggle to find a treatment that satisfied their expectations and needs. There are many factors involved that make this even more challenging such as numerous available treatment options according to migraine type (acute and prophylactic treatment<sup>3,41</sup>) or different treatment settings (emergency department [ED] or physician consult). Notably, patient preferences and values may not always align with the efficacy data of treatments or with what clinicians prioritize when making their recommendations for treatment. A study by Packard<sup>42</sup> found that clinicians prioritized pain relief while patients prioritized communication.

## Implications for practice

Findings illustrate the importance of patient experiences and opinions being heard, validated, and respected by their health-care professionals. Patients expressed the desire to be included in a SDM process.<sup>26</sup> To allow patients to make informed decisions, clinicians must be able to effectively educate patients. This requires clinicians to have up-to-date knowledge regarding migraine as a disease, its impact on patients' lives, and the evidence for its treatments. Migraine has been ranked the second overall cause for years lived with disability and the leading cause of years lived with disability in young people.<sup>43</sup> Despite this significant disability, findings showed that many patients feel they are not being taken seriously and neither is migraine as a disease. Barriers to care can also be addressed with education of patients and health-care professionals. Studies have shown that patients must traverse several barriers to obtaining effective migraine care. Lipton et al. provide a list that includes

TABLE 3 Summary of findings: Preferences about the treatment features.

Preferences about the treatment features (number of studies)	Findings statements	Studies	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Nonpharmacologic (14 studies)	Patients prefer nonpharmacological treatment option for prophylaxis, long-term reduction of symptoms, and overall health	Afifi (2019), Befus (2019), Belam (2005), Connor (2021), Cotrell (2002), Dekker (2012), Huddleston (2018), Meyer (2002), Morgan (2016), Peters (2003, 2004), Rutberg (2009, 2012, 2013) <sup>20,21,23–31,34–36</sup>	High confidence	One study with major concerns (Befus 2019), six studies with minor concerns (Belam 2005, Connor 2021, Cotrell 2002, Peters 2003, 2004, Rutberg 2013), and seven studies with no concerns (Afifi 2019, Dekker 2012, Huddleston 2018, Meyer 2002, Morgan 2016, Rutberg 2009, 2012). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Highly effective (4 studies)	Patients prefer highly effective treatments that reduce immediate migraine symptoms, decrease number of recurrences, and provide functionality	Befus (2019), Connor (2021), Friedman (2018), Rutberg (2009) <sup>23,26,29,37</sup>	Moderate confidence	Two studies with major concerns (Befus 2009, Friedman 2018), one study with minor concerns (Connor 2021), and one study with no concerns (Rutberg 2009). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Rapidity of action (1 study)	Patients prefer treatments with fast onset of action	Friedman (2018) <sup>37</sup>	Low confidence	The included study had major concerns regarding methodological limitations and small body of evidence. No concerns regarding coherence, relevance, and adequacy
Long-lasting effect (1 study)	Patients prefer treatment with long-lasting effect so that patient does not have to re-take the abortive treatment multiple times within the same day	Friedman (2018) <sup>37</sup>	Low confidence	The included study had major concerns regarding methodological limitations and small body of evidence. No concerns regarding coherence, relevance, and adequacy
Less costly and more accessible (5 studies)	Patients prefer treatment features that have lower cost or are more accessible and available	Befus (2019), Cotrell (2002), Khan (2015), Morgan (2016), Peters (2004) <sup>21,26,31,32,34</sup>	High confidence	One study with major concerns (Befus 2019), three studies with minor concerns (Cotrell 2002, Morgan 2016, Peters 2004), and one study with no concerns (Khan 2015). Major concerns regarding methodological limitations, minor concerns regarding coherence. There were no concerns regarding relevance and adequacy
Abortive versus prophylactic treatment (1 study)	Patients prefer awareness and knowledge about abortive as well as prophylactic treatment options, and may select either option based on the monetary, emotional, and social costs of abortive or prophylactic treatment	Dekker (2012) <sup>28</sup>	Low confidence	The included study had no concerns, but there was inconsistency in patients' views

(Continues)



TABLE 3 (Continued)

Preferences about the treatment features (number of studies)	Findings statements	Studies	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Self-management/self-delivery (6 studies)	Patients prefer treatments that can be self-administered and managed, increasing their feeling of autonomy	Connor (2021), Huddleston (2018), Matthews (2020), Morgan (2016), Peters (2003, 2004) <sup>20,21,27,29,31,38</sup>	High confidence	Four studies with minor concerns (Connor 2021, Matthews 2020, Peters 2003, 2004), and two studies with no concerns (Huddleston 2008, Morgan 2016). Minor concerns about methodological limitations, coherence, relevance, and adequacy

Abbreviation: CERQual, Confidence in the Evidence from Reviews of Qualitative Research.

"(1) consulting a prescribing health care professional; (2) receiving a migraine diagnosis; and (3) using migraine-specific or other appropriate acute treatments."<sup>44</sup> Only 26.3% of patients with episodic migraine and less than 5% of patients with chronic migraine traverse all three health-care barriers.<sup>44,45</sup> Patients with migraine may not seek consultation for a number of reasons, such as lack of access to health-care providers in their area, health insurance status, or misattribution of symptoms.<sup>44,46,47</sup> There is ongoing research evaluating educational programs for primary care physicians, general neurologists, and ED physicians regarding migraine and its treatments, all of whom are often the first points of contact for patients with migraine.<sup>48-51</sup> Additionally, there has been increasing attention by medical societies, such as the American Headache Society and the American Migraine Foundation, to ensure that people have access to evidence-based information regarding migraine through online resources and social media.<sup>52</sup>

Furthermore, there are data that "prescribing migraine education" makes an impact on migraine frequency and quality of life.<sup>53</sup> Per this review, individuals with migraine who participated in a prospective, migraine education program were more likely to have fewer headache days and also have improved headache-related disability scores over 12 months. This is added evidence that a collaborative, education-driven approach to migraine care is not only desired by patients but is helpful in meeting additional outcomes.

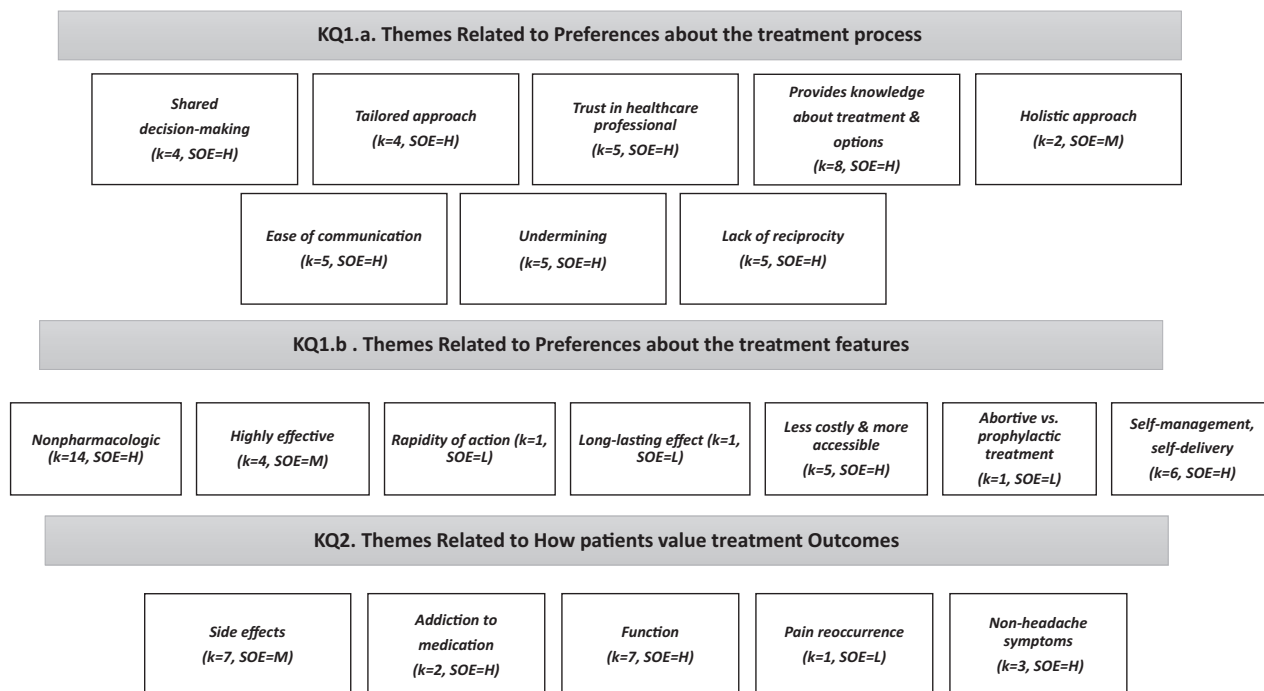
From a treatment features standpoint, patients expressed preference for non-pharmacologic treatment, long-lasting effect, high effectiveness, rapidity of action, lower cost and more accessibility, a self-management/self-delivery option; and had varying preferences for abortive versus prophylactic treatment. For each treatment feature identified by patients (i.e., pharmacologic vs. non-pharmacologic, long vs. short acting, etc.), there are diverse options available to meet the individual patient's needs. However, this requires clinician knowledge of these options. Furthermore, it requires access to these options, which is often limited by cost and insurance coverage. For example, non-pharmacologic treatment was identified as a patient preference. However, non-pharmacologic treatment options, such as neuromodulatory devices, are often cost prohibitive and insurance coverage is generally lacking.

Side effects, addiction potential, function, pain reoccurrence, and non-headache symptoms were identified as important treatment outcomes for patients. These prioritized outcomes highlight that migraine is much more than just a headache disorder. It is important for clinicians to be mindful of migraine symptoms beyond headache, such as aura, photophobia, phonophobia, and nausea/vomiting, and how migraine may affect the patient's functioning. Having patients keep a headache diary includes patients as active participants in their health plan.<sup>54</sup> This allows for monitoring of symptoms, function, and treatment effect. There are several formal tools designed to help quantify patient disability from migraine, such as the Migraine Disability Assessment,<sup>55</sup> and effectiveness of migraine treatments, such as the Migraine Treatment Optimization Questionnaire (mTOQ-4).<sup>56</sup> These tools can be used for clinical and

TABLE 4 Summary of findings: How patients value treatment outcomes.

Migraine treatment Outcomes (number of studies)	Findings statements	Studies	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
<i>Side effects (7 studies)</i>	Patients with migraine place high value on avoiding, reducing, knowing, or anticipating prior treatment side effects of treatment	Befus (2019), Dekker (2012), Friedman (2018), Meyer (2002), Peters (2004), Rutberg (2012), Speck (2020) <sup>21,24,26,28,36,37,39</sup>	Moderate confidence	Two studies graded as major concerns (Befus 2019, Friedman 2018), two studies with minor concerns (Peters 2004, Speck 2020), and three studies with no concerns (Dekker 2012, Meyer 2002, Rutberg 2012). Major concerns regarding methodological limitations, minor concerns regarding coherence and adequacy. There were no concerns regarding relevance
<i>Addiction to medication (2 studies)</i>	Patients with migraine placed high value on avoiding the potential for addiction to medications	Dekker (2012), Rutberg (2012) <sup>24,28</sup>	High confidence	Two studies graded as no concerns. There were no concerns regarding methodological limitations, coherence, adequacy, and relevance
<i>Function (7 studies)</i>	Patients with migraine placed high value on restoring, maintaining, or improving function over pain relief	Affi (2019), Befus (2019), Connor (2021), Dekker (2012), Meyer (2002), Ruiz de Velasco (2003), Rutberg (2009) <sup>23,26,28,29,35,36,40</sup>	High confidence	One study with major concerns (Befus 2019), two studies with minor concerns (Connor 2021, Ruiz de Velasco 2003), and four studies with no concerns (Affi 2019, Dekker 2012, Meyer 2002, Rutberg 2009). Major concerns regarding methodological limitations, minor concerns regarding coherence and adequacy. No concerns regarding relevance
<i>Pain reoccurrence (1 study)</i>	Patients with migraine placed high value on durable pain resolution, over short-term pain resolution, avoiding pain reoccurrence	Friedman (2018) <sup>37</sup>	Low confidence	The included study had major concerns regarding methodological limitations and small body of evidence. No concerns regarding coherence, relevance, and adequacy
<i>Non-headache symptoms (4 studies)</i>	Patients with migraine placed high value on avoiding non-headache symptoms such as nausea, vomiting, and sensitivity to light or sounds	Cotrell (2002), Peters (2005), Rutberg (2012), Speck (2020) <sup>22,24,34,39</sup>	High confidence	Three studies with minor concerns (Cotrell 2002, Peters 2005, Speck 2020), and one study with no concerns (Rutberg 2012). Minor concerns regarding methodological limitations, coherence, and adequacy. There were no concerns regarding relevance

Abbreviation: CERQual, Confidence in the Evidence from Reviews of Qualitative Research.



**FIGURE 2** Themes identified in evidence synthesis, confidence level, and number of supporting studies per theme. H, high; k, number of studies; L, low; M, moderate; SOE, strength of evidence.

research purposes to better understand and objectively document the experience of patients with migraine.

The valued outcomes of reducing side effects and addiction potential highlight a mismatch between current prescribing practices versus patient preference and evidence to support those prescribing trends. Guidelines recommend against the use of opioids and butalbital for acute treatment of migraine.<sup>57</sup> The current study documents that patients wish to avoid treatments with addiction potential. Despite this, opioids are frequently prescribed for the acute treatment of migraine.<sup>2,58–63</sup> Clinicians must be educated about the overall low or insufficient strength of evidence for opioids,<sup>3</sup> and higher rates of adverse effects.

Notably, patient preferences may sometimes conflict, for example, lack of side effects versus rapidity of action. Often when an acute treatment has a more rapid onset of action, generally due to faster time to peak concentration, it may also have more associated side effects.<sup>64,65</sup> Clinicians must have the knowledge and ability to discuss with patients these different treatment characteristics so that patients may weigh the pros and cons of each option.

Discussions among patients, health-care professionals, insurance providers and government agencies are required to ensure that all the relevant stakeholders are aware of the needs of patients with migraine and that based on their values and preferences, their needs are not currently being fully met.

Findings can be used to inform further service development and quality improvement at the patient, clinician, insurance provider, and governmental levels to help improve the lives and outcomes of people with migraine. We developed the following questions to guide health-care professionals to adequately address the needs of a patient living with migraine according to their preferences.

- Are health-care professionals properly trained and skilled in shared decision-making and aware of all treatment options?
- Are patient preferences taken into consideration when a treatment is discussed?
- Are health-care professionals offering pharmacologic and non-pharmacologic treatments to patients?
- Are patients satisfied with their clinic encounter and treatment decision process?
- Are patient outcomes and experiences routinely monitored and fed back into clinical encounters?

## Implications for research

Findings highlight two areas with major implications for research that are intertwined. The first is what should be the focus of this research and the second is how it should be conducted. Patients seek understanding of the pathophysiology of migraine and how it explains their symptoms. The diagnosis of migraine is based on clinical features rather than test results. As such, patients expressed feeling as though they did not understand the cause for their symptoms, and/or that their clinicians did not provide adequate or clear explanations for their symptoms. Continued research focusing on the pathophysiology of migraine is necessary to meet patients' need to better understand migraine as a disease and to develop biomarkers to help in diagnosis. Patients also expressed that it was important for them to understand how the treatments worked. A better understanding of migraine pathophysiology allows for mechanistically based treatment design.

Historically, studies of migraine treatment have focused on the migraine headache. Pain freedom and pain relief have been the most common endpoints used.<sup>2</sup> Research, especially clinical trials, should continue to focus on designing therapies that prioritize high effectiveness. However, other concepts, such as preventing occurrence, cost, and management of non-headache symptoms should be considered. Current recommendations for trial design encourage utilization of co-primary endpoints like most bothersome symptom, which would allow for evaluation of treatment effect on symptoms such as photophobia, phonophobia, nausea, and vomiting. Numerous patient-reported outcomes (PROs) have also been utilized or are in development to capture more fully the migraine experience, and to allow for more clinically meaningful endpoints.<sup>66</sup> Further research is required to establish the validity of these PROs.

Most of the trials on acute treatment of migraines assess the immediate side effects of the drugs under study. However, harms may develop with frequent or long-term use of medications, such as end-organ damage, or secondary conditions that may develop in the setting of consuming medications, for example, medication overuse headache, opioid use disorder, and overdose. More research evaluating side effects, particularly with long-term or frequent use, and addiction potential is required.

## Strengths and limitations

This is the first rigorously conducted and reported qualitative evidence synthesis of patient perceptions and experiences of acute migraine treatments, both the positive and negative, by a large number of adult patients. Although findings are generally descriptive, new insights that have potential to impact policy and practice were developed when the studies were synthesized.

This review has several limitations. As previously noted, patient preferences and values may be subject to selection bias. For example, studies that provided data on patient preferences about non-pharmacologic interventions, like chiropractic care,<sup>29</sup> acupuncture,<sup>23</sup> and physical therapy,<sup>25</sup> enrolled patients who may have self-selected to receive non-pharmacological therapies. This potential bias has been considered in the strength of evidence assessment. Additionally, confidence in findings was most precise regarding White adult North American women with migraine. Thus, a systematic distortion of the experience and preferences of people with migraine due to nationality, race, sex, gender, or sexual orientation is possible.<sup>67</sup>

Diversity, equity, and inclusion efforts such as developing guidelines that include a representative sample of population from a racial, ethnic, socioeconomic, and gender standpoint, are ongoing to help address this issue in migraine research.<sup>68</sup>

The review focused on patient perspectives and values regarding treatments rather than the evidence for efficacy or harm of these treatments. As such, it is important to recognize that the information shared regarding treatments reflects individual opinions and should

not be used to support a specific treatment but rather to understand a patient's experience with that treatment.

Only one of the included studies was funded by a public agency. Funding qualitative research can be challenging; however, this approach has demonstrated well-established contributions to decision-making as understanding values, attitudes, and complexity of interventions.<sup>69</sup> This is particularly important in chronic diseases with high burden to patients, such as migraine.

## CONCLUSION

Patient values and preferences were individually constructed, varied widely, and could be at odds with conventional medical perspectives and evidence of treatment effects. Considering the availability of numerous treatments for migraine, decision-making should incorporate patient values and preferences identified in qualitative research. Findings can help further service improvement, and guide choices and decisions in the context of a clinical encounter or a clinical practice guideline.

## AUTHOR CONTRIBUTIONS

*Study concept and design:* Mary E. Butler, Mohammad Hassan Murad, Meritxell Urtecho, Brittin Wagner, Zhen Wang. *Acquisition of data:* Brittin Wagner, Mohammad Hassan Murad, Meritxell Urtecho, Mary E. Butler, Zhen Wang. *Analysis and interpretation of data:* Mohammad Hassan Murad, Brittin Wagner, Meritxell Urtecho, Zhen Wang, Mary E. Butler. *Drafting of the manuscript:* Brittin Wagner, Meritxell Urtecho, Mohammad Hassan Murad, Mary E. Butler, Zhen Wang, Juliana H. VanderPluym, Rashmi B. Halker Singh, Jane Noyes. *Revising it for intellectual content:* Meritxell Urtecho, Mohammad Hassan Murad, Jane Noyes, Brittin Wagner, Mary E. Butler, Zhen Wang, Juliana H. VanderPluym, Rashmi B. Halker Singh. *Final approval of the completed manuscript:* Meritxell Urtecho, Mohammad Hassan Murad, Jane Noyes, Brittin Wagner, Mary E. Butler, Zhen Wang, Juliana H. VanderPluym, Rashmi B. Halker Singh.

## ACKNOWLEDGMENTS

This manuscript is based on work conducted by the Agency for Healthcare Research and Quality (AHRQ) Evidence-Based Practice Centers at the Mayo Clinic and University of Minnesota. The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services. We acknowledge three patients who reviewed the findings of this report and provided feedback: Katherine Rogers, Angela Murad, and Karin Merk.

## FUNDING INFORMATION

This research was funded through contracts from the Agency for Healthcare Research and Quality to the Scientific Resource Center,

HHSA 290-2017-00003C and the following Evidence-Based Practice Centers: Mayo Clinic Evidence-Based Practice Center, HHSA 290 2015 00013I; Minnesota Evidence-Based Practice Center, HHSA 290 2015 00008I.

## CONFLICTS OF INTEREST

**Dr. VanderPluym** reports receiving a research grant from Amgen.

**Dr. Halker Singh** reports consulting for Teva and Impel, and receiving a research grant from Amgen. All other authors report no conflicts of interest.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Urtecho M, Wagner B, Wang Z, et al. A qualitative evidence synthesis of patient perspectives on migraine treatment features and outcomes. *Headache*. 2023;00:1-17. doi:[10.1111/head.14430](https://doi.org/10.1111/head.14430)



## APPENDIX 1

## DETAILS OF THEMES IDENTIFIED REGARDING PREFERENCES ABOUT THE TREATMENT PROCESS

## 1. Shared decision-making

Patients preferred treatment processes that allowed them to receive explanations of their health and treatment options, be active participants in their care, and practice SDM with the health-care professional.<sup>26,44,45,46</sup> It is important to note that most participants were women.

Patients in three studies described how important it was for them to be engaged in a participatory conversation or talk with clinicians about migraine.<sup>26,47,48</sup> Patients in one study appreciated a treatment process that allowed their physical therapist's care to shift in its approach based on what the patient was saying to the physical therapist (quote 1.1).<sup>49</sup> Patients in another study experienced a shift from perceiving the health-care professional as "the one in charge" to perceiving themselves as having full involvement in the treatment decisions (quote 1.2).<sup>50</sup> Patients in one study who shared and discussed with their clinician described being "heard" (quote 1.3).<sup>51</sup>

Description of SDM across four studies is conceptualized as follows: in one of these studies, patients described preference for fully sharing their migraine-related experiences and concerns with the clinician, then receiving information or strategies from the clinician, followed by being able to ask questions of and receive helpful answers to their questions (quote 1.4).<sup>52</sup>

These descriptions of SDM overlap to some extent with other themes, such as Trust in the Health-Care Professional and Ease of Communication, but the latter themes do not represent the full process or sequence of SDM, and hence are presented as separate themes. Similarly, patients in one study<sup>53</sup> reported that SDM was absent where patients feel dismissed or not taken seriously by health-care professionals, which was separate theme that we present later (Undermining Patient Preferences).

## 2. Tailored approach

Across four studies, patients preferred treatment processes that were or could be tailored to them as an individual manner (quotes 1.5 and 1.6).<sup>54-56</sup> Tailored approach was also mentioned for different situations and circumstances (e.g., commuting or in the workplace) (quote 1.7),<sup>57</sup> to condition and treatment changes over time or due to information exchange.<sup>58</sup> Patients also preferred treatments that were tailored or appropriate to the interpersonal style of the clinician.<sup>59,70</sup>

## 3. Trust in the health-care professional

Patients preferred treatment processes in which they felt they could trust the health-care professional. Trust is found coherently present across studies where patients felt secure despite their own awareness of their vulnerabilities. One manifestation of trust was when the clinician was aware that the patient felt or was in a vulnerable position (quote 1.8),<sup>60</sup> patients may be afraid of not being taken seriously by the clinician (quote 1.9), or that the clinician may be unwilling or unable to be helpful to the patient (quote 1.10).<sup>61-63</sup>

In one study, trust in the health-care professional was demonstrated through a process in which providers listened to what the patient was saying and adapted the treatment approach.<sup>29</sup> Trust in the health-care professional featured treatment processes that naturally produced knowledge about migraine and treatment options for patients and clinicians.<sup>28</sup> Trust in the health-care professional was an important missing feature in one study among patients who reported previous experiences with providers who seemed to lack sympathy<sup>62</sup> (see Undermining Patient Preferences) and where patients may feel overburdened with a sense that they cannot "prove" their condition (see Lack of Reciprocity).<sup>33</sup>

## 4. Process provides knowledge and options

Patients preferred treatment processes that confer knowledge and advance treatment options for their condition.<sup>2,20,25,26,27,28,29,31</sup> These processes often allow the possibility of surprise: they allow the patient to try various treatments, to notice the impacts of various treatments,<sup>30</sup> and overlap with the features of SDM and Trust in the Health-Care Professional. For example, participants in one study reported that they continued in the study because the process of SDM and building trust in their clinician made them notice the positive impacts of treatment and the clinician-patient relationship, both of which were unexpected from their perspective (quote 1.11).<sup>29</sup> Patients in one study described an active gathering or learning process in which they gained alternatives to treatment options that may not work for them, as well as knowledge about how treatment processes may relate to migraine experiences and outcomes (quote 1.12).<sup>20</sup> Taken together, this treatment process feature is likely foundational to a Tailored Approach.

Patients in two studies noted development of a sense of ownership over migraine<sup>26</sup> and observing a surprising response to treatment (quote 1.13)<sup>30</sup> as well as the resulting ability to make good decisions for themselves. Patient self-monitoring is also impactful for revealing treatment preferences. In one study, migraine education helped patients monitor and control their migraine attacks and understand the likely impact of different treatments on their migraine outcomes (quote 1.14).<sup>66</sup> Patients in a different study found processes that provide knowledge and options as a positive experience for patients engaged in migraine self-management, where patients reported migraine management as a matter of "doing the work" themselves (quote 1.15).<sup>29</sup> In a study of pharmaceutical prophylaxis for migraine, patients described becoming aware of appropriate use versus overuse of acute treatments as part of a process wherein health-care professionals monitored patients' use of treatments and made recommendations for changes accordingly.<sup>28</sup> This study reported a shift from patients having limited awareness about the risks of overusing acute treatments before a migraine occurred, reporting that some patients who used excessive acute treatment mistakenly called it "prevention," and dread of clinician phone calls (due to fear of prescription nonrenewal due to too frequent use of medications) to patients reporting feeling appreciation for their clinician's concern and change in treatment approach based on a learning process shared by the patient and their clinician.

Finally, patients reported preference for processes in which they feel they are continuously learning from their clinician and receiving guidance in doing the right things while being ultimately responsible for their own actions.<sup>25</sup> These themes coincide with features of SDM and Tailored Approach and Trust in the Health-Care Professional.

## APPENDIX 1 (Continued)

### 5. Holistic approach to treatment

Patients preferred treatment processes that engage them in a learning conversation about holistic approaches to headache and non-headache aspects of migraine. Patients preferred processes that engage them as "whole persons," rather than processes that merely attend to symptoms (quote 1.16).<sup>67</sup> Where this feature is present, the patient feels they are in a participatory conversation, that they "now have options" (quote 1.17).<sup>68</sup> Related to processes that provide migraine knowledge and treatment options, patients in a focus group study explained their preference for a holistic approach because it helps them learn how non-headache areas are connected to migraine and/or that such areas can improve (e.g., posture, jaw, and migraine attacks).<sup>69</sup>

### 6. Ease of communication

Patients preferred treatment processes that ease the communication between the patients and the health-care team, especially for complex treatments such as behavioral intervention and self-administered techniques. In one study about chiropractic care, a patient reported that chiropractors provided more knowledge of this technique with exercises and homework for the patients (quote 1.18).<sup>29</sup>

Patients noted that some therapeutic interventions were challenging to handle on their own; therefore, having a health-care professional to adequately guide them through this process was beneficial (quote 1.19).<sup>31</sup>

### 7. Undermining patient preferences

This process features undermining patient experience, preferences, and abilities (impacting almost all of the process features highlighted above), including where information about migraine appeared, not only from health-care professionals but also from outside of health-care settings (e.g., advertisements).<sup>30,32</sup>

In both studies that report on finding preferences for SDM, patients reported a need for information from clinicians about migraine as a condition as well as about treatment options.<sup>26,30</sup> In one of these studies, patients reported the absence of SDM where insurance or health system changes excluded them from clinicians or treatments they may have worked to find (quote 1.20).<sup>31</sup> In other study, patients reported absence of SDM where they perceived low or lack of provider knowledge about migraine (quote 1.21).<sup>30</sup>

In a study of prophylaxis for migraine, trust in the health-care professional occurs when clinicians take patients and their conditions seriously, as indicated by listening, demonstrating awareness and consideration of patients' fears of not being taken seriously, and helping ensure that patients "have a say" in their own treatments.<sup>28</sup> In a study of patient access to triptans, patients' previous experiences when clinicians seemed unsympathetic about migraine was followed by lack of trust (quote 1.22).<sup>32</sup> In a different study, patients discovered information about their condition and treatment options from sources other than health-care professionals (quote 1.23).<sup>28</sup> In this and another study, mistrust of the clinician's knowledge followed after patients experienced lack of sympathy and relative lack of knowledge about migraine and treatment options.<sup>32</sup>

### 8. Lack of reciprocity

Patients preferred reciprocal treatment processes in which mutual respect can be exercised between patient and clinician in the forms of patient inclusion, as well as information-gathering and explanation-sharing on the parts of both the clinician as well as the patient. When patients were excluded from treatment options (e.g., due to change in insurance) and were not consulted about treatment approaches, they experienced their exclusion as intentional "like you do not count" and as a one-sided dismissal by bureaucracy (quote 1.24).<sup>34</sup> Patients described not being given an explanation for being excluded from access to treatment options in conjunction with their experience of health-care professionals attempting to control treatment without consulting them (quote 1.25). Patients also described feeling as though they had done more research about treatment options than clinicians had (quote 1.26).<sup>30</sup>

Other studies found cases in which patients felt not taken seriously or dismissed in processes involving individual health-care professionals. For example, a patient in a focus group study described a verbal communication from a health-care professional where they felt they were being dismissed, explaining that the clinician told them to "live with it" (quote 1.27).<sup>34</sup> Whether patients experience lack of reciprocity as a lack of access due to not being paid attention to or not being taken seriously,<sup>33</sup> a loss of access to preferred treatments without being consulted by bureaucracy, or as intentional exclusion from exploring or learning about migraine treatments with their clinicians, this feature of treatment processes stands in contrast to patient preference for mutual respect and undermines foundations for trust in the health-care professional and SDM (quote 1.28).<sup>33</sup> In one study, patients felt the inability to initiate contact or request follow-up with their clinician was a lack of reciprocity (quote 1.29).<sup>33</sup> Patients in one study of a physical therapy intervention described the structure of their treatment with their provider as unequal (quote 1.30). This study identified Trust in the Health-Care Professional as a feature ameliorating the unequal structure of migraine treatment (quote 1.31).<sup>20</sup>

## APPENDIX 2

### DETAILS OF THEMES IDENTIFIED REGARDING PREFERENCES ABOUT THE TREATMENT ITSELF

#### 1. Non-pharmacologic treatment

Availability and knowledge of non-pharmacological treatment options is important, even when these treatment options are not selected. When non-pharmacologic options were selected, patients described feeling relief about no longer needing to fill prescriptions for medication and reported newly obtained satisfaction with over-the-counter medications. Some patients described their selection of non-pharmacologic treatment as following a period of heavy or overuse of medications (quotes 2.1 and 2.2).<sup>35</sup> In another study, non-pharmacologic treatments motivated patients to learn more about their condition and become more aware of their body (quote 2.3).<sup>29</sup> In some studies of medications, where non-pharmacologic treatment options were not selected, patients acknowledged their need for medication along with expressing a desire to use less medication or find non-drug treatment options.<sup>26</sup> In one study of non-pharmacologic treatment for migraine, all study participants took some sort of medication for migraine. They acknowledged the need for this, but repeatedly expressed a desire to use non-pharmacological approaches for prevention, long-term migraine reduction, and contributions to overall health (quote 2.4).<sup>26</sup> Another study found that some patients, especially women considering pregnancy, were dissatisfied with a perceived emphasis on drug therapy (quotes 2.5, 2.6, and 2.7).<sup>34</sup> Patients in a study exploring the opinions, motives, and expectations of patients regarding prophylactic therapy described how using daily preventive pills would make them feel emotionally unhealthy (quote 2.8).<sup>28</sup>

#### 2. Highly effective

Interviews of patients who received migraine treatment in the ED showed the overwhelming majority (76%) emphasizing the importance of treatment effectiveness to them.<sup>37</sup> Many quotes from respondents were consistent in stating that this was their number one priority (quotes 2.9 and 2.10). Similar findings were stated in a study of experiences of acupuncture among women with migraine (quote 2.11).<sup>23</sup> There was also one study that reported patients not convinced that their medications were effective (quotes 2.12 and 2.13).<sup>26</sup>

#### 3. Rapidity of action

Only one study of intravenous (IV) medication in the ED, touched on rapidity of action. Rapidity of action was reported as a theme in response to the question, "What was good about the IV medication you have received for headache in the ED?" and provided a representative quote from among patients preferring or appreciating rapidity of action (quote 2.14).<sup>37</sup>

#### 4. Long-lasting effect

Only one study of IV medication in the ED touched on long-lasting treatment effect. This study reported a theme in response to the question, "What was good about the IV medication you have received for headache in the ED?" and provided a representative quote from among patients preferring or appreciating prolonged duration of efficacy (quote 2.15).<sup>37</sup>

#### 5. Less costly and more accessible treatment

Treatment cost as a barrier to specific treatments and the cost of access interruptions were addressed in five studies. Participants with low socioeconomic status frequently mentioned financial constraints (quote 2.16).<sup>34</sup> A study reports patient selection of pharmacologic treatments is based on cost preferences, describing how a patient used Imigran only for her severe migraine attacks, otherwise she relied on over-the-counter drugs. This patient also limited her use of Imigran because of the personal cost, but this cost preference was balanced with effectiveness (quote 2.17).<sup>33</sup> The patients were frustrated by "the bureaucrats" in managed care companies who mandated their choices of physicians and medications (quote 2.18). This study also reports related additional costs to access interruptions, describing lack of affordability as particularly infuriating for those who had spent significant time and effort finding a physician with whom they felt comfortable or a medication that worked for them, only to be told that because of a change in insurance coverage, they had to change physicians, medications, or both.<sup>34</sup> Lack of access was also identified as costly for financial, mental, and emotional well-being. A study of access to triptans for episodic migraine attacks reports that many private insurers impose quantity limits on triptans, with physician and patient participants reporting patient anxiety regarding exceeding monthly coverage limits (quote 2.19).<sup>32</sup> One study noted that frequently it was cost that prevented patients from trying alternative therapies.<sup>34</sup> The study participants, who had consulted alternative therapists, compared these consultations to the traditional medical consultations. They gave little descriptions on how effective they found alternative therapy, but they expressed satisfaction with the time and advice offered by alternative therapists. Although not all the participants had consulted an alternative therapist, they generally expressed an interest in what alternative therapies had to offer.

#### 6. Abortive versus prophylactic treatments

Dekker et al. interviewed 20 patients with migraine (9 had experience with prophylactic medications).<sup>28</sup> The interviews provided heterogeneous views in which some patients preferred abortive treatments and some did not (quotes 2.20, 2.21, and 2.22).

#### 7. Self-management and self-delivery option

Matthews and Kneipp reported on self-management strategies used by patients including those during an attack (medication, meditation, caffeine) or between attacks (diet, exercise, hydration, hot showers, etc.). Of note, these self-management strategies were learned from one trusted individual who also had migraine, labeled as the "trusted migraineur."<sup>38</sup> In Morgan et al., cognitive behavioral therapy was the self-management tool used (quote 2.23).<sup>31</sup> Various aspects of self-management were also described in Peters et al. (quote 2.24).<sup>20</sup> Another patient assessed the type of headache and accordingly selected treatment to achieve the best outcome (quote 2.25). Decision was an active stage that described the patients' choices for management. Decision, the outcome of evaluation, was often a compromise between their options and perceptions (quote 2.26).<sup>35</sup>

## APPENDIX 3

### DETAILS OF THEMES IDENTIFIED REGARDING OUTCOMES VALUED BY PATIENTS

#### 1. Side effects

Many studies reported on the importance of side effects to patients (quote 4.1).<sup>21</sup> In interview data collected by Friedman et al. of patients in the ED, 27% emphasized different concerns (quotes 4.2, 4.3, 4.4, and 4.5).<sup>37</sup> In Meyer's study, patients were concerned about having a stroke (quote 4.6).<sup>36</sup>

#### 2. Addiction to medication

A negative outcome reported by two studies was addiction to medication, especially in long-term treatment, such as prophylaxis. In one study, the authors reported that more than half of the patients stated that daily use of tablets for migraine would make them feel emotionally unhealthy.<sup>28</sup> Other negative factors included the fear of drug dependency, a low assessment of their own capacity for compliance, and the negative reactions of persons in their direct surroundings (quote 4.7). Rutberg and Ohrling reported that the use of medication made patients worry about the risk of becoming addicted (quote 4.8).<sup>24</sup>

#### 3. Function

Restoring, maintaining, or improving function as an outcome of migraine treatment was reported in seven studies. In one study patients mentioned that they would consider taking treatment for their migraines depending on their daily workload (quote 4.9).<sup>36</sup>

Patients expressed their preference for treatment that keeps them completely functional (quotes 4.10 and 4.11).<sup>26,29</sup> Another patient described their concern about being functional and taking long-term treatment (quote 4.12).<sup>21</sup>

#### 4. Pain reoccurrence

In one study patients emphasized the importance of avoiding pain reoccurrence (quote 4.13). Of note, this theme as a treatment outcome overlaps with the theme of long-lasting treatment effect, which is a treatment feature.<sup>37</sup>

#### 5. Non-headache symptoms

Migraine-associated symptoms such as nausea, vomiting, and sensitivity to light and sound were outcomes of importance for patients (quotes 4.14, 4.15, and 4.16).<sup>22,24</sup> Numerous quotes from Speck et al. highlighted how patients were distressed by light sensitivity, nausea, and visual concerns.<sup>39</sup> Another study mentioned how patients prioritize the non-headache symptoms over pain itself, despite high costs (quote 4.17).<sup>34</sup>