

# BMJ Open Living with chronic migraine: a qualitative study on female patients' perspectives from a specialised headache clinic in Spain

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## ABSTRACT

**Objectives** The aim of this study was to explore the views and experiences of a group of Spanish women suffering from chronic migraine (CM).

**Setting** Headache clinic at a university hospital in Madrid (Spain).

**Participants** Purposeful sampling of patients that attended a specialised headache clinic for the first time between June 2016 and February 2017 was performed. The patients included were females aged 18–65 and with positive diagnoses of CM according to the International Classification of Headache Disorders (third edition, beta version), with or without medication overuse. Accordingly, 20 patients participated in the study with a mean age of 38.65 years (SD 13.85).

**Design** Qualitative phenomenological study.

**Methods** Data were collected through in-depth interviews, researchers' field notes and patients' drawings. A thematic analysis was performed following appropriate guidelines for qualitative research.

**Results** Five main themes describing the significance of suffering emerged: (a) the shame of suffering from an invisible condition; (b) treatment: between need, scepticism and fear; (c) looking for physicians' support and sincerity and fighting misconceptions; (d) limiting the impact on daily life through self-control; and (e) family and work: between understanding and disbelief. The disease is experienced as an invisible process, and the journey to diagnosis can be a long and tortuous one. Drug prescription by the physician is greeted with distrust and scepticism. Patients expect sincerity, support and the involvement of their doctors in relation to their disease. Pain becomes the main focus of the patient's life, and it requires considerable self-control. The disease has a strong impact in the work and family environment, where the patient may feel misunderstood.

**Conclusions** Qualitative research offers insight into the way patients with CM experience their disease and it may be helpful in establishing a more fruitful relationship with these patients.

## Strengths and limitations of this study

- This study presents new data on the perception of chronic migraine (CM) among female patients attending a specialised headache clinic for the first time.
- In-depth interviews and descriptions of patients' drawings were used to collect qualitative data as they enable the patient's experiences with chronic pain to be analysed.
- Although the results cannot be extrapolated to the entire population of patients with CM, they can help physicians better understand the impact of the disease and the patients' perspectives.
- The findings of this study may help to improve the management of patients with CM.

## INTRODUCTION

Migraine is one of the main causes of disability worldwide,<sup>1</sup> with a global prevalence of 12%.<sup>2</sup> The International Classification of Headache Disorders (third edition, beta version: ICHD-3 beta) defines chronic migraine (CM) as a headache registered on more than 15 days a month, over more than 3 months, that on a minimum of 8 days each month has the typical characteristics of migraine, or responds to triptans or ergot drugs.<sup>3</sup> CM is always a progression from episodic migraine (EM),<sup>4</sup> and as the frequency of headaches increases, it is common for the clinical features of migraine to change and characteristic migraine episodes combine with other less painful episodes that resemble tension-type headaches. In some cases, patients with CM suffer headaches of such persistence that it becomes impossible to distinguish individual episodes of pain.<sup>5</sup> CM is the most common cause of chronic daily headache, with a global prevalence between 0.5% and 5%,<sup>6</sup> and an estimated 2.5% of patients with

EM progress to CM each year.<sup>7</sup> CM mainly affects females (with a 2.5–6.5 higher frequency than in males), and it is associated with other risk factors, such as age, time since migraine onset, overuse of analgesics or low socioeconomic status.<sup>7–10</sup> Frequently, comorbidity exists with other disorders such as chronic pain, anxiety, depression and obesity.<sup>8</sup>

Standardised questionnaires, such as the Headache Impact Test (HIT-6), the Migraine Disability Assessment Scale or the Short Form-36, have demonstrated that CM is more debilitating and causes a stronger reduction in quality of life than EM.<sup>11–13</sup> Nevertheless, the true life experience and impact of the disease are extremely personal, and there are aspects that cannot be measured with scales or questionnaires. Individual perspectives and the account of pain are relevant, inasmuch as one's life experiences, aspirations and emotional needs must be considered when treating the individual.<sup>14</sup> Qualitative research (QR) can provide a more holistic picture that may be more meaningful to practitioners.<sup>15 16</sup> Indeed, QR has already been used to analyse how migraine affects a patients' work, leisure, social and family life.<sup>17–20</sup> It has also been applied to the analysis of patients' expectations of the healthcare system and different therapeutic resources, including alternative therapies, and control strategies adopted by the patients themselves.<sup>21–27</sup> However, no qualitative study to date has focused on CM, the most debilitating form of migraine. By using qualitative methods, we aimed to answer the following research question: 'what is the lived experience of patients with CM?'.<sup>28</sup> Thus, the purpose of this study was to explore the experiences and perspectives of a group of Spanish women suffering from CM.

## METHODS

### Design

A qualitative phenomenological study was carried out to address the experiences of Spanish women with CM. In the field of qualitative studies, phenomenology attempts to understand other people's lived experiences by using first-person narratives and other sources such as personal letters, diaries and drawings.<sup>29 30</sup> Moreover, phenomenological studies aim to mitigate the effects of any preconceptions (bracketing).<sup>31 32</sup> In our study, bracketing was achieved by carefully recording the positions taken by the researchers beforehand and by using in-depth interviews as the main data collection tool.<sup>28 32</sup> In this way, we sought to avoid the researcher's influence on the data and reveal the nature of the phenomenon through the patients' accounts.<sup>29</sup> Phenomenology has proved to be useful to explore the individual meaning of chronic pain.<sup>30</sup>

### Research team

Prior to the study, the position of the researchers was established according to their previous experience and their motivation.<sup>29</sup> Nine researchers (six men and

three women) participated in this study, three of whom (DPC, BNM, CFP) had experience in qualitative study designs and were not involved in clinical activity and had no prior relation with the participants. The remaining investigators (LSH, DMC, LLF, HGM, DGA, MLC) had clinical and research experience with neurological patients.

### Participants and sampling strategies

Patients with CM (n=20) that attended the headache clinic at the neurology department of the Hospital Clínico San Carlos (Madrid) for the first time were enrolled on the study between June and December 2016. All patients were recruited at their first visit to the clinic to ensure that none of them had experienced a significant improvement—or even a reversal to EM—at the time of the study. The interviews were scheduled in the following 2 weeks. Purposeful sampling based on the relevance to the research question and not clinical representativeness was employed,<sup>33</sup> and sampling continued until redundant information from the data analysis was achieved.<sup>29</sup>

The subjects included in the study were females aged 18–65 years old and with a diagnosis of CM according to ICHD-3 beta,<sup>3</sup> with or without medication overuse. The exclusion criteria included: (a) the occurrence of other headaches, primary or secondary, different to medication overuse headache; (b) other chronic pain syndromes; (c) serious systemic and/or psychiatric disorders; (d) inability to communicate in Spanish or to sign the informed written consent.

### Data collection

Data were collected between June 2016 and February 2017. Based on the phenomenological design, first-person data collection tools (in-depth interviews and drawings) and researcher's field notes were used simultaneously.<sup>29</sup> In-depth interviews (unstructured and semistructured) were used as the main tool for data collection. With participants 1–10, the interview started with an open question: 'What is your experience with CM?'. Thereafter, the researchers listened carefully, noted the key words and topics identified in the patients' responses and used their answers to ask for and clarify the content.<sup>29</sup> In this way, relevant information was collected from the perspective of the patients. Also, during the interviews, researchers used prompts or probes: (a) to encourage the patients to provide more detail ('Can you tell me a bit more about that?'), (b) to encourage the participant to keep talking ('Have you experienced the same thing since?'), (c) to resolve confusion (paraphrasing of something that the patient had said) and (d) to show full attention by the researcher ('That's really interesting, please tell me more').<sup>29</sup>

A first analysis was performed on the unstructured interviews of participants 1–10. This analysis revealed some relevant topics that required further study, thus making it necessary to include a second stage of data collection. This second stage (participants 11–20) consisted of

**Table 1** Semistructured interview questionnaire

Issue studies	Questions
Disease	How would you describe your pain? And your condition? What does it mean to you? What elements, factors or situations affect your experience of pain? How much do you know about your headache and the disease you suffer? How do you feel during a migraine crisis? What does it mean to you? How has your headache evolved over the past few years? What do asymptomatic periods mean to you? What aspects of the disease are most relevant to you?
Diagnoses	What prompted you to seek medical help for the first time? Could you explain the process of your diagnosis? What doctors and specialists did you visit, what tests were performed, etc? Could you describe the most relevant aspects of the attention you received from your GP and from your neurologist? What is your opinion regarding the time it took to reach a diagnosis of your pain?
Treatment and strategies	Treatment What do you consider to be the most relevant aspect of the treatment that has been prescribed to you? What do you think about the treatment? Do you adhere to the treatment? Why? Strategies Are there any strategies you adopt to cope with your pain? Have you received any advice to control your pain that differs from that of your doctor? Have you taken any substance other than the treatment prescribed to control your pain? Why? Have you tried any alternative medicines? Yoga, reiki, homeopathy. Why?
Doctor–patient relationship	How would you describe your relationship with your doctor? What is the most important thing for you? How do you think this relationship influences your disease? What do you think that the physicians think about migraine? Have you had to visit A & E services and for what reason? What did it mean to you to have to visit the A & E services? What was the most relevant aspect of having to visit A & E?
Daily life	What are the most relevant changes you have made in your life because of CM? How much and in what ways does CM restrict you?
Working environment	Has your job suffered because of your condition? How do you think that your workmates and your boss perceive your disease? Have you ever hidden your headache at work? Why?
Socio-family environment	What have been the most relevant changes in your social and family life? And with respect to your partner? Has your relationship with your partner, friends and close relatives changed because of your condition? If so, in what way? Do you usually hide your migraine from your partner, family or friends? Why? How do you believe other people perceive migraine?

A&E, emergency department; CM, chronic migraine; GP, general practitioner.

semistructured interviews that were based on a question guide designed to gather information regarding specific topics of interest (table 1).<sup>29</sup>

All the interviews were tape-recorded and transcribed verbatim, recording 1951 min of interviews overall. The first 10 interviews ranged in length from 73 to 135 min (mean 102.9; SD 22.34), and the second set of interviews ranged from 70 to 139 min (mean 103.86; SD 37.61). The interviews were held at the patient's home (n=10), a coffee shop (n=3) or in a private room at the hospital (n=7), depending on the patient's preference. Interviews were carried out at a time when patients were not experiencing pain (n=5) or when they suffered only mild (n=3)

or moderate (n=12) pain. None of the patients postponed their interview even when experiencing some degree of pain. No third party was present at the interviews apart from the participant being interviewed.

At the end of the interviews, the patients provided drawings that gave further insight into how they viewed their illness.<sup>18 34 35</sup> Thus, when the interview reached the point where the participant had no more new information to offer, they were asked to draw a picture of what it is like to live with CM. Participants were provided with a blank piece of paper and 24 coloured crayons for their drawing. The interview then continued with a description of the picture starting with the question: 'What does the

picture represent?' Then researchers asked the patients to describe the content of their drawings and the reasons for their choice of colour, spatial organisation and composition. Patients' drawing descriptions and researcher field notes were part of the analysed data. Throughout data collection, these sources supported the previous ones and were often used for triangulation.<sup>29</sup>

Sociodemographic and clinical data were also recorded for each participant, as well as their Beck Depression Inventory (second edition: BDI-II)<sup>36</sup> and State-Trait Anxiety Inventory (STAI)<sup>37</sup> scores. In qualitative studies, the collection of sociodemographic and clinical data helps to understand patients' experiences and narrations, helps to situate them in a concrete context and serves to achieve the transferability of the results.<sup>29</sup>

The full literal transcription of each of the interviews, the patients' drawing descriptions and the researchers' field notes were all collated to perform a qualitative analysis. Finally, data collection was pursued until the researcher achieved information redundancy, at which point no new information emerged from data analysis (in our study, this occurred with patient 20).<sup>29</sup>

### Data analysis

A thematic analysis was performed, which began by analysing the most descriptive content in order to arrive at meaningful units, and then went into further depth to produce thematic code groups (ie, grouping meaningful units referring to the same issue or with the same content until the main topics emerged). To identify the relevant content, researchers read and reread the data at three different levels: literally, interpretively and reflexively.<sup>29</sup> In this way, an increasing level of abstraction and complexity was established for the analysis from meaningful units to thematic code groups and finally themes.<sup>29</sup> Each interview was analysed by two researchers, separately. After the analysis, meetings were held to show and compare the results obtained. These meetings were held with a frequency of 2 weeks, either face-to-face or by videoconference.

For clarity, a matrix was built with the results obtained from the analysis. Subsequently, joint meetings were held to combine the results of the analysis. In the case of differences in opinion, theme identification was performed based on consensus among the research team members. After that, the research team held joint meetings to show, combine and integrate the results of the analysis from each matrix. At that point, all researchers analysed and discussed the matrixes results and identified final themes by consensus among all members.<sup>29 38</sup> The final outcome was the identification of themes that represented the patients' experiences of suffering CM. No qualitative software was used to analyse the data. The analysis was performed by the researchers who had contact with the patients (DPC, BNM, CFP).

### Rigour

The guidelines established by the Consolidated Criteria for Reporting Qualitative Research<sup>39</sup> were followed. The

data verification method consisted of: (a) cross-triangulation by the researchers, which involved planning sessions where the cases analysed by each team member were presented in order to reach a consensus; (b) auditing of the material obtained from the participants by an external independent researcher; and (c) postinterview and postanalysis patient verification.<sup>40</sup>

### Ethical considerations

The study was approved by the Clinical Research Ethics Committee at the 'Hospital Clínico San Carlos' (code: 16/054-E; see technical online supplementary appendix 1). Informed consent and permission to record the interviews was obtained from each patient.

### RESULTS

Twenty female patients with CM were enrolled on this study, and the mean age of the participants was 38.65 years (SD 13.85). Five patients had completed basic education, six secondary education and six higher education. At the time of the study, two patients were in the course of completing their university degrees and one patient was finishing her secondary education. All patients had an active lifestyle as two of them were housewives, while the remainder were either studying or working outside the home. At the time of the study, the mean time since the onset of migraine was 20.2 years (SD 13.23), and the median of time since migraine had become chronic was 2 years (IQR 0.8–5 years). In the 3 months prior to the interviews, the patients had presented a mean of 24.6 headache days per month (SD 4.7), with 12.85 days a month of moderate to intense pain (SD 6.03) and the use of symptomatic medication (paracetamol, non-steroidal anti-inflammatory drugs, triptans or opiates) on a mean of 14.1 days (SD 8.91) a month. All the patients except one had received one or more oral preventive medication, with no significant response or with an insufficient response. However, none of the patients had been treated with nerve blocks or botulinum toxin injections prior to recruitment. According to the BDI-II scores, five patients suffered mild depression and three moderate depression. Moreover, 14 patients showed some degree of anxiety as a state and 15 as a trait according to the STAI scores (see [table 2](#) for the full demographic and clinical features of all the participants).

When the material obtained from the participants was analysed, five specific themes emerged: (a) the shame of suffering from an invisible condition; (b) treatment: between need, scepticism and fear; (c) looking for physicians' support and sincerity and fighting misconceptions; (d) limiting the impact on daily life through self-control; and (e) family and work: between understanding and disbelief. These five emerging themes were evident in the narratives taken directly from the patients' interviews and patients' drawings descriptions (see examples in [table 3](#)).

### Theme 1: the shame of suffering from an invisible condition

CM is experienced with **frustration** given that patients fail to achieve complete pain relief despite specialist referral

**Table 2** Demographic and clinical features

Patient no.	1	2	3	4	5	6	7	8	9	10
Age, years	27	50	56	63	23	41	47	21	28	27
Time since migraine onset	13 years	20 years	36 years	49 years	9 years	20 years	30 years	2 years	18 years	3 years
Time since CM onset	7 months	3 years	2 years	6 years	9 months	6 months	5 years	2 years	6 years	2 years
Aura	Visual	No	No	Visual and sensory	No	Visual	Visual	No	Visual	No
Days per month of headache (last 3 months)	21	25	20	25	26	16	15	30	26	20
Days per month of moderate-to-severe headache (past 3 months)	5	20	20	5	13	6	15	6	12	10
Days per month of acute medication use (past 3 months)	3	13	16	5	26	6	15	6	12	12
BDI-II, score and interpretation*	2	8	0	9	24	2	23	17	15	5
	No depression	No depression	No depression	No depression	Moderate depression	No depression	Moderate depression	Mild depression	Mild depression	No depression
STAI-S score and interpretation†	4	18	0	40	43	2	49	35	32	11
	No anxiety	Moderate anxiety	No anxiety	Severe anxiety	Severe anxiety	No anxiety	Severe anxiety	Severe anxiety	Severe anxiety	No anxiety
STAI-T score and interpretation‡	14	21	1	37	46	11	48	35	35	6
	No anxiety	Moderate anxiety	No anxiety	Severe anxiety	Severe anxiety	No anxiety	Severe anxiety	Severe anxiety	Severe anxiety	No anxiety
Current acute medication (last 3 months)	NSAIDs Triptans	Paracetamol NSAIDs Triptans	Paracetamol NSAIDs Triptans	Paracetamol Opioids	Paracetamol NSAIDs Triptans	Paracetamol NSAIDs Triptans	Paracetamol NSAIDs Triptans Opioids	Paracetamol NSAIDs Triptans	Paracetamol NSAIDs Triptans	Paracetamol NSAIDs Triptans
Prior prophylactic treatments	Flunarizine	-	Flunarizine Propranolol Topiramate Zonisamide Valproate Gabapentin Amitriptyline	Topiramate	Nebivolol	Mirtazapine Nebivolol Pregabalin	Amitriptyline Flunarizine Propranolol	Amitriptyline	Atenolol Topiramate Mirtazapine	Amitriptyline
Current prophylactic treatment (last 3 months)	-	Nebivolol Magnesium	-	Venlafaxine Amitriptyline Flunarizine	-	-	Nebivolol Magnesium	-	Amitriptyline	Topiramate

  

Patient no.	11	12	13	14	15	16	17	18	19	20
Age, years	20	47	56	46	29	33	52	32	22	53
Time since migraine onset	10 years	30 years	30 years	27 years	9 years	8 years	37 years	16 years	4 years	33 years
Time since CM onset	7 months	30 years	4 years	10 years	1 year	4 years	7 months	2 years	2 years	5 years

Continued



Table 2 Continued

Patient no.	11	12	13	14	15	16	17	18	19	20
Aura	No	No	Visual	Visual and sensory	Visual and sensory	No	Visual and sensory	Visual	Sensory	Visual and sensory
Days per month of headache (past 3 months)	28	30	20	25	30	22	30	27	30	26
Days per month of moderate-to-severe headache (past 3 months)	15	15	12	25	15	10	20	20	5	8
Days per month of acute medication use (past 3 months)	20	30	5	25	15	20	30	0	15	8
BDI-II, score and interpretation*	6 No depression	1 No depression	8 No depression	24 Moderate depression	8 No depression	11 Mild depression	0 No depression	5 No depression	11 Mild depression	13 Mild depression
STAI-S, score and interpretation†	27 Moderate anxiety	14 Moderate anxiety	20 Moderate anxiety	30 Severe anxiety	13 Moderate anxiety	38 Severe anxiety	1 No anxiety	14 Moderate anxiety	12 No anxiety	21 Moderate anxiety
STAI-T, score and interpretation‡	23 Moderate anxiety	22 Moderate anxiety	31 Severe anxiety	39 Severe anxiety	20 Moderate anxiety	38 Severe anxiety	28 Moderate anxiety	15 No anxiety	17 Moderate anxiety	26 Moderate anxiety
Current acute medication (past 3 months)	NSAIDs Triptans	NSAIDs Triptans	Paracetamol NSAIDs	Paracetamol NSAIDs Triptans	NSAIDs Triptans	Paracetamol NSAIDs Opioids	NSAIDs Triptans	-	NSAIDs Triptans	Paracetamol NSAIDs
Prior prophylactic treatments	Magnesium	Topiramate Propranolol Flunarizine	Propranolol	Duloxetine Pregabalin	Amitriptyline	Venlafaxine	Amitriptyline	-	Amitriptyline Topiramate Nebivolol	-
Current prophylactic treatment (past 3 months)	Nebivolol Amitriptyline	Venlafaxine	Duloxetine	Topiramate	-	-	Nebivolol Zonisamide	Nebivolol Amitriptyline	-	-

\*BDI-II scores: 0-9, no depression; 10-18, mild depression; 19-29, moderate depression; ≥30, severe depression (for Spanish adults).

†STAI-S scores: 0-12, no anxiety; 13-28, moderate anxiety; ≥29, severe anxiety (for Spanish adult women).

‡STAI-T scores: 0-15, no anxiety; 16-29, moderate anxiety; ≥30, severe anxiety (for Spanish adult women).

BDI-II, Beck Depression Inventory, second edition; CM, chronic migraine; NSAID, non-steroidal anti-inflammatory drugs STAI-S, State Scale of the State-Trait Anxiety Inventory; STAI-T, Trait Scale of the State-Trait Anxiety Inventory.

**Table 3** Narratives from patients with chronic migraine

Themes	Narratives
1. The shame of suffering from an invisible condition	<p><b>Helplessness:</b> "Helplessness, the sensation of wanting to but not being able to... others go out, they're as fresh as a daisy, and you, you are completely worn out without even leaving home, that is what it's like, at times you're worse than those who went out on the town even though you stayed in." (patient 9, 28 years old, unstructured interview).</p> <p><b>Uncertainty:</b> "You give up hanging around with your friends, you give up loads of stuff, because you don't know when you'll have a bout of headache. I'm still with my episodes, without knowing when they'll come. I've been housebound for the last month, in case the pain comes back." (patient 18, 32 years old, unstructured interview).</p> <p>"I can't draw anything clear, specific, just flashes, it's completely different everyday, there's nothing stable." (patient 7, 47 years old, drawing description).</p> <p><b>An invisible disease:</b> "It becomes frustrating. At first, I had a scan, then a magnetic resonance, I had many tests and they found nothing! And they told me that everything was normal. I couldn't prove it and even if they do tests, they can't demonstrate anything. I was embarrassed to go to the doctor, it was as though I was wasting their time." (patient 9, 28 years old, unstructured interview).</p> <p><b>A long and winding path to diagnosis:</b> "I've seen a lot of doctors. It's been, 7 years I think, and finally, I'm now being seen at the neurology department. You get tired because you say: and now another one, and another..." (patient 14, 46 years old, semistructured interview).</p>
2. Treatment: between need, scepticism and fear	<p><b>Distrust and scepticism:</b> "It is true that the neurologist told me that the treatment was very much trial and error, and that we have to keep trying until getting the pain under control... That doesn't give me much confidence, does it? I thought it was more standardised, it hurts, it's due to this disease and then they give you the right pill...but there are not magic pills. I don't trust treatment." (patient 1, 27 years old, unstructured interview).</p> <p><b>Reaching normality:</b> "I just want to have a normal life, do the same stuff as everyone. I just want to do things without feeling pain, or at least, with a mild one. But, tablets sometimes don't work. I can see myself reading, walking my dog, but always in pain." (patient 16, 33 years old, drawing description).</p> <p><b>Depending on analgesics:</b> "They're now a part of me [the pills]... a part of my life... I need them to kill the pain, I live like that, thinking that I'm going to be in pain and I don't have the pills on me, and you become distressed because you're thinking: I'm going to be in pain and I don't have them." (patient 3, 56 years old, unstructured interview). "If I think that I don't have them, I'm going to suffer, it's a constant struggle with my own self, with my pain. If I've not got them on me I'm afraid that I'll be in pain and I'm continually thinking about it, I can't control it. I can forget my cell phone but not my pills." (patient 3, 56 years old, unstructured interview). "... eventually you end up with pills in all your bags, with pills everywhere. I don't have a bag or jeans in which I haven't got ibuprofen, paracetamol. But that's also very frustrating." (patient 10, 27 years old, unstructured interview).</p> <p><b>Pharmacological cocktails and self-medication:</b> "And when the pain starts, apart from everything I have to take, I'm already saying: Hey! I haven't taken this today, let's see if it does anything. Because it seems like always taking the same thing is as if you're not doing anything." (patient 14, 46 years old, semistructured interview).</p> <p><b>Lack of adherence to preventive treatments:</b> "My doctor explained to me how important it was to take medication daily, even though there were side effects. I told the doctor, how can you put me on a treatment that already caused me side effects! I remember perfectly, that it caused me side effects... [imitating her doctor] 'No, you try it, and if you have any side effects just stop taking it...' (patient 1, 27 years old, unstructured interview). "I don't like taking medication to avoid the pain... I don't like it because I've never taken so many pills in a day, because if I'm in pain, of course I'll take five pills, and if it hurts more, I'll take 6 or 7. I don't like the feeling that I'm taking pills all the time." (patient 11, 20 years old, semistructured interview). "What I don't want is to get hooked... I don't like addictions, so, because I think that... that it's like being really addicted, I won't be happy or I'm not going to feel OK, you understand? Why take medication if I don't have pain?" (patient 6, 41 years old, unstructured interview).</p>
3. Looking for physicians' support and sincerity, and fighting misconceptions	<p><b>Clear information and sincerity:</b> "I haven't been given an explanation, I was told its name and little else. The first neurologist told me that I had chronic headache, with no explanation, nothing. The next doctor told me that I had chronic migraine because I'd had them for more than 15 days or something like that. But I think that they should explain something more about the aetiology, it's because of this, because of that." (patient 19, 22 years old, semistructured interview).</p> <p><b>Support and involvement:</b> "They abandon you in the sense that the doctors relax and say that there is nothing to be done. Also, in terms of treatments that really work, with all the advances in medicine, and they still can't make the pain go away." (patient 3, 56 years old, unstructured interview). "It's like no-one has paid any attention to me! When a person has headaches on two or 3 days a week, that seems a lot to me, right? Sometimes I even leave the doctor's depressed and I say: but what have I got that no-one pays any attention to me? Will nobody ever take me seriously?" (patient 7, 47 years old, unstructured interview). "At my first neurology appointment, I was not given any contact phone number, I left the consultant with some medication and if it doesn't do me any good, I wasn't to have another appointment with the neurologist for 3 months. To have that phone number, even if you never call, makes you feel more secure, being able to ask for help if you need it." (patient 12, 47 years old, semistructured interview).</p> <p><b>Situations that hinder doctor-patient relationship:</b> "It seems that they are trying it on with you, they know that this medication isn't going to do anything for you and yet still they prescribe it, if they know that it isn't going to have any effect on you then why do they prescribe it?" (patient 14, 46 years old, semistructured interview). "I have the feeling that when they listen to you, they think that pain is something normal that happens to women. Like the joke: she's got a headache." (patient 7, 47 years old, unstructured interview). "Is there a history of headaches in your family? And you go to another doctor and the same question: and is there any family history...? There comes a point when I stopped mentioning it. It seems like they give up on you, they relax when they know there is a family history [of migraine]. Even when it comes to performing tests, they tell you, 'Since there is a family history there is nothing we can do, if this is migraine, that's that...'. Come on! you give them information that they use against you as they please." (patient 3, 56 years old, unstructured interview). "If the GP doesn't consider it sufficiently important so as to refer you to a neurologist, to perform a CT scan, a magnetic resonance or whatever it takes, you're stuck. And for years and years. I had to be hospitalised eight times before I was finally referred to the specialist. It sounds pretty bad, right? After 9 years." (patient 15, 29 years old, semistructured interview).</p>

Continued

Table 3 Continued

Themes	Narratives
4. Limiting the impact on daily life through self-control	<p><b>Everything revolves around pain:</b> "Migraines make me cut myself off, they don't let me be the person I am. They mean I can't live my life. It's sad that thanks to a migraine you have to cancel yourself, you can't carry on with your life as normal. When you are somewhere, there you are and suddenly, it comes on and you have to go. It affects you to the point that you have to isolate that is not even considered serious! I want to end this, I want my head to stop hurting, I want it to stop affecting my whole life. I need it to stop to live a normal life... to forget worries that others don't have." (patient 5, 23 years old, unstructured interview).</p> <p><b>Resignation:</b> "It's like a life with a chronic illness that ultimately wears you out because you're always in pain. In the end, you end up getting used to the pain and you resign yourself to living with it, and you think it's never going to change: 'Another shitty day.' The pain ends up being something normal and I got used to it. No... [she clicks her tongue] the word is I became resigned to it." (patient 8, 21 years old, unstructured interview). "There comes a time when you become used to living with the pain. Then, the day that there is no pain, you say: 'Oh, great! There is no pain at all...'" (patient 13, 56 years old, semistructured interview).</p> <p><b>Change of lifestyle:</b> "You are conditioned by the lifestyle you have to follow, where you work, how much you work. Everything, family life... it affects everything. You can't lead a normal life, you can't go out dancing, to dinner, to the cinema. It's not the influenza, it's not the cancer thank god! But sure, it's something that changes the way you live." (patient 15, 29 years old, semistructured interview). "It restricts my daily activities. It limits the time I can spend with my friends and even the desire to do sport. It has affected my lifestyle and my mood too. I'm more down, less lively, whereas I've always been very independent, very active, it's a little bit like being disabled." (patient 8, 21 years old, unstructured interview). "I quit drinking coffee. I've switched to decaf because all of that is bad for you... I had a perfume that I couldn't use because my head started to hurt... and so, now, what can I do? What can I drink, what can I take?" (patient 17, 52 years old, semistructured interview).</p> <p><b>Mood changes and irritability:</b> "My family does influence me, especially my husband and son. I just start to shout and I get into a bad mood. What happens to them? Well, they pay for my suffering and I realise that that's not fair." (patient 14, 46 years old, semistructured interview). "Well, when I am like that, so bad tempered and I don't want to have anything to do with anybody, I get in such a bad mood that I can't stand anyone, you're irritable, you do not want anyone to talk to you, no-one to tell you anything... and since they don't understand, on top of that you get furious, you get frustrated and you even feel isolated." (patient 10, 27 years old, unstructured interview).</p> <p><b>Self-control:</b> "You try not to let it affect you, to control everything, to deal with it, to be conscious of everything that might cause you pain... but it is very tiring, it's exhausting. Sometimes I get up and think 'Oh, no!', and I take a pill and just go back and rest." (patient 9, 28 years old, unstructured interview). "I have so many things to do that I cannot always be lying down in pain. Who's going to clean? Cook? My husband helps me a lot but there are things that no matter how much someone helps you, it is better to do them yourself. Besides, I don't like feeling like an invalid. I try to tolerate the pain as much as I can." (patient 6, 41 years old, unstructured interview).</p> <p><b>Pregnancy:</b> "Migraines during pregnancy were terrible, tremendous. It was the biggest sacrifice I've ever made in my life, as you can't take anything except paracetamol. It affected me a lot, because you're limited to mild drugs and you can't take the stronger ones. I spent the whole of my pregnancy here at home. I stayed completely away from the outside world to avoid any situation that could trigger my pain. I didn't take the underground, the bus. I went to the supermarket at 2, 3 or four in the afternoon, when there were fewer people, not in the morning, not at night. Being pregnant changed everything for me, radically." (patient 15, 29 years old, semistructured interview).</p> <p><b>Lack of understanding at work:</b> "My workmate told my bosses that if I had a headache I should take a pill and that it was no excuse not to go to work. Things like that every day." (patient 1, 27 years old, unstructured interview). "I think that like any other pain, those who don't suffer from it don't understand. Ignorance leads to incomprehension. It is a condition that has a bit of a bad reputation." (patient 2, 50 years old, unstructured interview).</p> <p><b>Hide symptoms and diagnosis:</b> "You often try to hide it. You hide it because people don't understand how a simple headache can affect you so strongly. Besides, I don't want to be a nuisance. They may think that you are a hassle or a drag, or that you are pathetic." (patient 3, 56 years old, unstructured interview). "I've always treated pain as a personal matter. I don't confide in anyone because I don't think they can help me. It would even compromise my credibility in terms of my ability to present projects. It would weaken me, you wonder whether a person who always has a headache would be able to do some things or not." (patient 15, 29 years old, semistructured interview). "If I had a business I would also be sick to death of a person who has been working with me for 3 months and has missed work three times, 3 days in three different months. Then, eventually it's going to happen [getting fired]. Imagine that you have a worker who is good at her job but you do not know when she's going to get sick, you can't count on that person because she may have to go home and perhaps you're left stranded on the busiest day of work. Who in their right mind would hire a person like that?" (patient 5, 23 years old, unstructured interview).</p> <p><b>Obligation to stay at work:</b> "I don't stop doing my job because of my headaches because if you start missing work, then you can pack your bags and go. I don't think anyone would like an employee, who is often off sick, whatever the illness. I always try and fulfil all my obligations." (patient 18, 32 years old, semistructured interview). "I was taken by ambulance to A &amp; E and my partner [hairdresser] finished her shift at 10:00 pm, because she had to deal with all the people that I should have looked after. And while I was with the doctor, I kept repeating [to the doctor] 'I have to go back', and the doctor said to me, 'Don't you see that you can't?'" (patient 5, 23 years old, unstructured interview).</p> <p><b>Understanding in the family:</b> "I know that they want to help, they are more interested and ask frequently. Obviously, they are closer than my co-workers. They try to understand my pain, to understand me." (patient 18, 32 years old, semistructured interview).</p> <p><b>Scepticism in the family:</b> "Powerlessness, they don't believe you! It really hurts! And there comes a point where you don't even say anything because if they are not going to pay attention to you, then what for. They think you're making excuses." (patient 9, 28 years old, unstructured interview). "They cannot understand that you have this kind of headache, they do not know how much it hurts because they compare it with the headaches that they have, and of course, they don't hurt as much. Then ... There she is again with her headaches." (patient 10, 27 years old, unstructured interview).</p> <p><b>Concern about the children:</b> "I should have been paying more attention, he used to wake up very early to study, I should have been aware to stop him from getting up so early in the morning. He has started with headaches and they are very strong. Last Tuesday we were at A &amp; E all afternoon... I should have been more vigilant and stopped him from seeing how much they hurt me." (patient 2, 50 years old, unstructured interview). "And my son is just starting, as a 14-year-old he complains of headaches a lot. He complains a lot but I still think he's too young to have headaches. It's been a couple of years now. Has he copied me or are they really painful? I think I have influenced him in some way. I don't know." (patient 14, 46 years old, semistructured interview).</p>
5. Family and work: between understanding and disbelief	





and the use of medication. All patients indicate a feeling of **uncertainty** when they observe how changes in their lifestyle and following standard recommendations fail to guarantee pain relief. Most of them describe CM as an **invisible disease** as their illness cannot be objectively demonstrated through diagnostic tests. Some patients admit feeling **ashamed** of seeking medical help for an invisible and little recognised disease. The **arriving at a diagnosis** is described as a long and tortuous **process**, reminiscent of an obstacle course. Many had to visit several doctors before being diagnosed with CM.

### Theme 2: treatment: between need, scepticism and fear

The use of pharmacological drugs is perceived with **distrust and scepticism** by most patients, since acute treatment (symptomatic) does not provide complete pain relief and preventive treatment does not completely avoid pain resurgence. Patients do not believe they will become pain free and, to them, a **successful treatment** should reduce pain to levels that would allow them to live a **'normal'** life and to get on with their lives.

Paradoxically, and despite distrust of analgesic and other symptomatic treatments, some patients recognise that they need to **have analgesic medication** at hand wherever they go and whatever they do. Having the medication handy reassures the patients, as they can take this medication if pain emerges. The majority of patients admitted to having at some stage taken analgesic medication that they had used before, often in a **cocktail**, or to **self-medicating** with unprescribed substances.

Long-term preventive treatments are not well accepted, and some patients do not adhere to them or they abandon them. Many patients read the patient information leaflet, and they become **apprehensive about the potential short and long-term adverse effects**, some of which they have even experienced in the past and reproach being prescribed the same kind of drugs anew. They are also sceptical when prescribed medication that includes antidepressants, antiepileptic or antihypertensive drugs, as they feel these are not relevant to their situation. Many patients are dubious about the effectiveness of preventive medication, and some of them abandon the treatments when they experience no reduction in pain as they are not willing to continue taking a large number of pills. Some patients also reported being afraid of **becoming addicted** to these treatments, as they must be taken daily, in addition to painkillers. Thus, many of them finally opt for controlling their pain with analgesics or other symptomatic treatments.

### Theme 3: looking for physicians' support and sincerity and fighting misconceptions

Patients do not expect a complete cure as they have assumed their pain is chronic. Some **obstacles** appear between patients and doctors. However, they do expect **truthful information and sincerity** from their doctors regarding the prospects of treatment, the progress of the disease and its significance. Most patients prefer to be

presented with real alternatives, which offer them options (and hope) of controlling or lessening the pain, and to be provided with reliable information about their disease. They also appeal for **support and involvement**, describing how they feel isolated when having to deal with their pain and how they need to feel the support of their doctors, whereby their disease must involve both of them.

Conversely, all patients identify **situations that hinder the physician–patient relationship**, such as: when a doctor prescribes a treatment that has already been tried unsuccessfully in the past, when inefficient treatments are maintained for a long time, when migraine is viewed as a minor symptom or affliction, when stereotypes about women ('they are more nervous and stressed') are used to explain the disease, when a family history of migraine is considered a limiting factor to perform exploratory tests and when referral to specialists is delayed.

### Theme 4: limiting the impact on daily life through self-control

Pain is a constant theme in the patients' life, **everything revolves around pain**. The majority of patients convey **resignation** at not being able to live completely pain free and they have learnt to **accept that they must live with it**. Nonetheless, patients attempt to **change their habits for fear** that they may trigger pain. This **change in lifestyle** is the consequence of the fact that everything revolves around pain. Moreover, those changes have an impact on the patients and on their partners and family. Many patients also suffer **mood swings and irritability**, which affect their relationship with partners, family and friends. For this reason, they live in a **constant state of self-control**. They can't allow pain to overwhelm them and rule their lives. Keeping up this demanding level of self-discipline on a daily basis can be challenging, particularly at times of higher emotional stress. Only one participant (patient 15) spoke of the impact of migraine **during pregnancy**, a patient who experienced anxiety in anticipation of pain as the use of painkillers was restricted.

### Theme 5: family and work: between understanding and disbelief

Patients encounter a **lack of understanding** at work, where workmates and managers are reluctant to believe that a headache could have such a strong effect. Many of them try to **hide the symptoms and diagnoses for fear of being discredited and losing their jobs**. Paradoxically, the majority of patients describe how they **force themselves to continue to work** or to return early from sick leave despite the pain, in order to avoid overburden their colleagues.

Most patients grant that they find more understanding in their family circles than at work. However, **there is a certain degree of disbelief** even among **family members** that their pain could be so debilitating or that they are not exaggerating their pain. Some patients are **worried that they might have contributed to their children** suffering migraine in the future by having submitted them to stress, being unable to attend family events (celebrations, school meetings, etc), because their children might imitate their

behaviour (staying in a dark room) or because they might have passed it on in their genes.

## DISCUSSION

Our results show how pain becomes the central focus in the life of patients with CM and it demands a high level of self-control. The illness is experienced as an invisible process, and the route to a diagnosis can be long and arduous. Medication does not produce complete pain relief, and prescriptions are perceived with scepticism. It is expected that doctors will be sincere, supportive and become involved in the patient's disease. This condition has a strong impact on the patient's work and family circles, where they often feel misunderstood.

To the best of our knowledge, this is the first study to describe the experiences of patients with CM using a qualitative analysis. QR has previously been applied to analyse the impact of migraine or of 'chronic daily headache'—in general—on patient's lives<sup>22–27</sup>; however, this is the first study to focus specifically on CM as defined by the ICHD-3 beta diagnostic criteria. The patient's accounts, together with sociodemographic and clinical data, were collated to provide an in-depth insight of the patients' situation. Different data collecting tools were used in order to extract more information.<sup>29</sup> Yet this study still has some limitations concerning generalisability that limit the extrapolation of our results to the whole population with CM. Chiefly, the study was limited to women, and as such, it does not reflect the impact of CM in men, although a population in which it is much less common. Second, the study was performed on patients attending a specialised headache clinic for the first time; therefore, our findings do not extend to patients with CM who have not visited a headache clinic or specialist, and likewise, we have not analysed the experiences of patients treated or managed in a specialised headache clinic for some time. This limitation could have influenced our results since purposeful sampling could have included women who were particularly dissatisfied with prior medical care. Another issue that might have influenced the results was the fact that three of the interviews were conducted in coffee shops; although the participants chose the coffee shop as a reliable and comfortable place, the environment in this setting could have limited confidentiality.<sup>38</sup>

Our results are consistent with previous studies that reveal that migraineurs, for the most part women, experience helplessness and a lack of control over their own life.<sup>17 18 22 41–43</sup> Acceptance of the disease as well as the uncertainty of success to calming the pain and preventing migraine attacks (by a change of lifestyle and by following medical recommendations and treatment) can be a way to regain control over the disease.<sup>17 22</sup>

Migraine has already been referred to as an invisible affliction.<sup>18 43</sup> In addition, patients with migraine are thought to construct a representation of their illness based on five dimensions: beliefs about the disease aetiology, the diagnostic label and associated symptoms,

the impact of the disease, the disease duration and the existence of a cure and control.<sup>43</sup> Flaws in any of these dimensions can lead to wrong assumptions,<sup>44</sup> including disregarding migraine as a real disease<sup>39</sup> or its consideration as a minor disease,<sup>24 25</sup> consequently generating shame in patients for seeking help.<sup>41</sup> Invisibility could account for visits to different practitioners,<sup>41</sup> as well as underdiagnosis or delayed diagnosis.<sup>45 46</sup>

Our results show that while patients are wary of the treatments prescribed to them, they take the medication to control the impact of CM on their lives. Patients with migraine and chronic daily headache have previously been said to distrust treatments,<sup>18 22</sup> based on the failure to achieve complete pain control or to prevent further episodes.<sup>15 18 41</sup> It has also been shown how patients take medication in order to feel safer and to feel that they are regaining control of their life.<sup>17 18 22 44</sup> The patients' low expectations and fear of side effects justify why headache sufferers find using acute medications more acceptable than using prophylactic drugs on a daily basis.<sup>25</sup> Radat *et al*<sup>43</sup> showed that migraine is perceived as successive crises but not as a progressive disease, which can explain why some patients resent long-term treatments that must be taken continuously without immediate effect.

Doctor–patient relationships are of paramount importance in order to actively engage the patient in taking control of the disease and adhering to treatments.<sup>25</sup> Our patients expect their doctor to become involved in their disease, consistent with previous studies that also found that the relationship between doctors and patients must be based on sincerity, honesty, communication and understanding of the patient's experience, prioritising this over achieving symptom remission.<sup>47 48</sup> Previous studies reported that patients with chronic daily headache are more satisfied with doctor consultations when management is shaped to their needs and when they feel that they are listened to and their concerns are understood.<sup>22 25 43</sup> Rutberg and Öhrling,<sup>18</sup> and Varkey *et al*<sup>22</sup> showed that patients commonly feel that they are not taken seriously, a sense of not being believed or that the physicians lack knowledge about migraine prevention. Previous studies also document a prevailing general belief that migraine is a 'women's disorder', which exacerbates gender bias in seeking help and diagnosis.<sup>49 50</sup>

As occurred in our patients, pain has previously been described as the centre of everything, having an impact on all dimensions of the patient's life, their family and social relationships.<sup>22 24 41 43</sup> Patients' perceptions of the impact of their disease vary depending on the patients' commitments (work and family), their belief in their ability to cope and their ability to fit their lives around their headaches.<sup>22 24</sup> Our results also agree with previous studies that described an attitude of resignation and withdrawal from activities,<sup>22 41 43 44</sup> as well as mood swings, irritability and aggression that hinder personal relationships and work.<sup>18 43</sup> Pain management may require a high degree of self-control, vigilance and constant involvement, all of which can affect the patient's quality of life.<sup>17 18 41 51</sup> As



previous studies show,<sup>17 18 41</sup> patients with migraine have a choice between strict compliance with recommendations (increasing the probability of avoiding pain, although involving more stress and life restrictions) and a more permissive approach, accepting that it won't be possible to control all the factors that potentially trigger pain (with less life restrictions but a higher risk of pain).

Special consideration must be given to migraine during pregnancy; while pain improves for the majority of pregnant women, a small number experience a worsening of migraine particularly during the first and third trimesters.<sup>52 53</sup> Whenever pain does not cease during pregnancy, the medication and/or alternative therapeutic options available to women are limited<sup>52</sup>; this was the case in one of our patients.

Our results coincide with those of other authors describing how patients experience certain disbelief when talking about their pain in social circles and often hide their disease and its symptoms.<sup>17 18 24 44</sup> Patients with chronic headache and migraine hide their disease for fear of losing their job, due to a lack of understanding by workmates/family, and given the notion that migraine is unacceptable in society.<sup>18 22 24 44</sup> Headache is not accepted in its full magnitude in the patient's social circles, and as such, it is regarded as an excuse to interrupt social and work obligations.<sup>17 18 44</sup> With regards the workplace, migraine has a considerable impact on a patients' ability and working efficiency during pain episodes, leading to changes in the workplace, and in the specific job tasks they can perform.<sup>18 44</sup> Paradoxically, to avoid being brought into doubt, many women push themselves to continue working despite suffering a migraine attack.<sup>18</sup>

In agreement with previous studies,<sup>27 44</sup> our patients were worried about the potential emotional impact their disease might have on their children, as they may on occasion be unfit to attend family events, they suffer mood swings, among others. Moreover, it has previously been shown how women that suffer migraines are insecure about their ability to take care of their own children, their condition influencing the patient's self-esteem as mothers and spouses.<sup>44</sup>

In conclusion, this study provides insight on how CM is experienced in a group of Spanish women attending a specialised headache clinic. Our results are in line with previous data based on patients with migraine or chronic daily headache. Moreover, our findings shed light on how CM may impact the lives of patients in a similar situation and may have important implications for clinical practice. Patients need the involvement and support of their doctors and the patient–doctor relationship must be viewed as an important element in the strategy to improve the management of CM. Knowing the patients' experiences can probably contribute to a better communication between clinicians and patients and to a greater compliance with treatments. Our study also provides grounds to guide further research into quality of life of patients with CM. In particular, it will be interesting to analyse the experience of patients who have undergone specific

treatments for CM, such as botulinum toxin injections, and those who have been treated at specialised headache clinics for some time.

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