

# BMJ Open Understanding the diagnoses and medical care experience of patients with new daily persistent headache: a qualitative study in Spain

Domingo Palacios-Ceña <sup>1,2</sup>, Blanca Talavera <sup>3</sup>, Víctor Gómez-Mayordomo,<sup>4</sup> David García-Azorin <sup>3</sup>, María Gallego-Gallego,<sup>5</sup> María Luz Cuadrado,<sup>6</sup> Ángel Luis Guerrero-Peral<sup>3</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr Blanca Talavera;  
[blanca.talavera@hotmail.com](mailto:blanca.talavera@hotmail.com)

## ABSTRACT

**Objective** To explore the experiences of patients suffering from new daily persistent headache (NDPH) regarding the diagnostic process, treatment and medical care.

**Design** A qualitative phenomenological study was conducted.

**Setting** A specialised headache unit at two university hospitals in Spain between February 2017 and December 2018.

**Participants** Patients diagnosed with NDPH according to the International Classification of Headache disorders (third beta edition).

**Methods** Purposeful sampling was performed. Data were collected using unstructured and semistructured interviews, researchers' field notes and patients' drawings. An inductive thematic analysis was used to identify significant emerging themes from interviews, field notes and descriptions of patients' drawings. Also, Guillemin's proposal was used to analyse the contents of drawings.

**Results** Nineteen patients with a mean age of 45.3 were recruited. Four main themes emerged: (1) Seeking a diagnosis, patients visit many doctors without receiving a clear answer and their diagnosis is delayed; (2) Self-medication—minimising pill intake, medication is ineffective, and therefore, some patients discontinue treatment, or are flexible with how they take medication; (3) Trying other non-pharmacological options, many patients turn to other therapies and complementary and/or alternative therapies as a second option, however these are ineffective and (4) Medical care, with two subthemes, referrals and lacking continuity of care, and building the doctor–patient relationship. Patients describe how the referral breaks the continuity of care, and how they identify the traits of a doctor who is approachable and which behaviours the doctor should avoid when caring for patients.

**Conclusions** An in-depth knowledge of the beliefs and expectations of patients with NDPH will allow the professional to establish a relationship of trust, which will improve the patients' knowledge of which therapies are the most appropriate, and to establish expectations based on the relationship with the doctor, and not only on patients' beliefs.

## Strengths and limitations of this study

- This is the first study to describe the experiences of new daily persistent headache (NDPH) patients regarding their medical care.
- An innovative combination of unstructured followed by structured interviews and descriptions of patients' drawings were used to collect qualitative data.
- The results cannot be extrapolated to the entire population of patients with NDPH.
- Double and independent coding and analysis of qualitative data was performed.

## INTRODUCTION

New daily persistent headache (NDPH) is an idiopathic headache syndrome characterised by the abrupt onset of an unremitting, daily, continuous headache without a history of an escalating headache pattern and not attributable to any other primary or secondary headache disorders.<sup>1</sup> The striking feature of this condition is its abrupt onset. A distinguishing feature of NDPH is that most patients can pinpoint the exact date of onset of symptoms.<sup>2 3</sup> Headache onset may occur in relation to an infection or influenza-like illness, febrile illness, minor head injury, extracranial surgery, a stressful life event and a single Valsalva event.<sup>3 4</sup> Men and women are almost equally affected; however, earlier reports suggest that NDPH is a female-predominant disorder.<sup>3 5 6</sup>

This type of headache is usually bilateral, and rarely side shifting. The nature of the headache can be throbbing, pressing or stabbing, and the comorbid symptoms in NDPH patients include nausea, vomiting, photophobia, sleep disturbances, blurred vision, neck stiffness and sensory disturbances.<sup>1 3 5</sup> Two clinical subtypes of NDPH exist: a self-limited form which resolves spontaneously

without treatment and a refractory, persistent form in which the headaches continue for years.<sup>3 7</sup> As a result, NDPH can continue for years to decades after onset and can be extremely disabling for the patient.<sup>3 8</sup> Frequently, there is comorbidity with other processes such as anxiety, depressive symptoms, somatisation and pain catastrophising.<sup>9</sup>

In clinical practice, treatment is aimed at matching the predominant headache phenotype; nonetheless, most therapies are generally ineffective or only partially effective.<sup>7</sup> Not surprisingly, symptomatic medication overuse is very common among patients with this disorder and should be identified. However, in most patients, a detoxification does not alter the course of the illness.<sup>2</sup> There is lack of evidence regarding the effectiveness of any pharmacological, surgical or non-pharmacological treatment in patients with NDPH.<sup>3 5 7 10</sup> There are reports of effectiveness of neuromodulator drugs, mexiletine, tetracycline, doxycycline, ketamine, botulinum toxin and nerve blocks, and in patients with NDPH.<sup>2 3 7 11</sup>

In Spain, the majority of healthcare is provided by the national health system, in addition to private healthcare services.<sup>12</sup> The national health system is conformed of primary care where health promotion, disease and disability prevention and chronic pathology management are carried out; and specialised care (hospitals and specialist care centres) that manage highly complex problems and acute diseases, as well as surgical procedures.<sup>12</sup> Regarding the management of headache pain, patients first go to their general primary care physician (Family and Community Medicine specialist), and based on their clinical judgement may refer patients to other medical specialists in specialty care for pain management, such as specialists in neurology and anaesthesiology-resuscitation.<sup>13–15</sup> For headaches (in the absence of trauma), the specialist of reference is the neurologist.<sup>15 16</sup> Patients may also be referred to special units such as 'Pain units' (run by anaesthesiologists) or 'specialised headache units' (run by neurologists).<sup>16 17</sup> However, traditionally most hospitals do not have specialised units in headache diagnosis and treatment.<sup>17</sup> In both public and private hospitals, it is more usual to have specialised consultations in the neurology services.<sup>17</sup> Depending on financial availability, all patients can go to private healthcare for diagnostic tests, seeking treatment and further medical assessment.

Currently, the treatment of primary headaches is faced with many challenges, such as adverse events, addiction and medication overuse.<sup>18</sup> Management difficulties in headache treatment can be overcome by paying closer attention to patient reports and narratives, and by facilitating greater patient involvement during the treatment process.<sup>18 19</sup> Qualitative research and patients' narratives can provide a more holistic picture that may be more meaningful to practitioners.<sup>19–22</sup> However, only one qualitative research has focused on NDPH and to date,<sup>23</sup> no qualitative study has examined how patients with NDPH perceive the diagnostic process and medical care. The

purpose of this study was to explore the experiences and perspectives of a group of patients suffering NDPH regarding the diagnostic process, treatment and medical care.

## METHODS

### Design

A qualitative phenomenological study<sup>24 25</sup> was conducted based on Husserl's framework.<sup>26 27</sup> 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>26 28 29</sup> Also, phenomenological studies aim to mitigate the effects of any preconceptions (bracketing).<sup>30 31</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>27 30 31</sup> In this manner, we sought to avoid the researcher's influence on the data and to reveal the nature of the phenomenon through the patients' accounts.<sup>26</sup> The guidelines for conducting qualitative studies established by the Consolidated Criteria for Reporting Qualitative Research<sup>32</sup> and the Standards for Reporting Qualitative Research<sup>33</sup> were followed (<https://www.equator-network.org/>). Seven researchers (four men, three women) participated in this study who were experienced in qualitative research and clinical work with headache patients.

### Setting, participants and sampling strategies

Participants included patients with NDPH attending the Headache Units at the Neurology Departments of Hospital Clínico Universitario de Valladolid and Hospital Clínico San Carlos de Madrid were recruited between February 2017 and December 2018. The Headache Units at these hospitals are specialised units aimed at improving the efficiency of the diagnostic and therapeutic process, reducing unnecessary complementary examinations, overuse of analgesic medication and inappropriate visits to the emergency room or doctor's office, and increasing the use of preventive treatments and patient education.<sup>17 34</sup> In phenomenological studies it is common to include participants based on purposive sampling.<sup>26</sup> Purposive sampling can be defined as the selection of individuals based on specific purposes associated with addressing the research study's question or aim.<sup>24 35 36</sup> Participant recruitment and data collection was ended when the information gained from the interviews becomes repetitive<sup>26</sup>; in our study this situation occurred after including 19 participants.

The study subjects included males and females aged 18–65 years old and with a diagnosis of NDPH according to the International Classification of Headache Disorders, third Beta edition.<sup>37 38</sup> Secondary headaches were excluded in all patients based on a complete medical history, plus a blood tests, contrast-enhanced MRI and cerebrospinal fluid pressure assessment. Moreover, primary headaches,

other than NDPH, were also ruled out, including chronic migraine, chronic tension-type headache and hemicrania continua. The exclusion criteria were: (1) other headache types different to NDPH, either primary or secondary; (2) other chronic pain syndromes; (3) serious systemic and/or psychiatric disorders; (4) inability to communicate in Spanish or to sign the informed written consent and (5) lack of informed consent from the patient.

### Patient and public involvement

First, researchers informed all the participants of the study design prior to them agreeing to participate. The study design was pre-established, and the participants were unable to modify the same. Second, participants involved in the study helped researchers identify the research questions in order to create a semistructured question guide. The questions of the semistructured interviews were based on unstructured previous interviews where the participants were able to describe their experience and perspective without limitations and to develop their own relevant content. Once the researchers constructed the question guide, it was presented to the first nine participants so that they could enrich the guide with those questions they considered relevant to their experience with NDPH. Also, participants were involved in confirming the data obtained at the various stages of data collection and analysis. To verify the analysis performed for each interview, half of the participants were contacted, all of which confirmed the analysis performed by the researchers.

### Data collection

Based on the phenomenological design, first person data collection tools (unstructured and semistructured interviews and drawings) and researcher's field notes were used simultaneously.<sup>26 29</sup> Previous studies<sup>29 39 40</sup> show how in the case of headaches and other conditions, the use of drawings in combination with interviews is a useful tool in data collection and analysis, because it helps to continue data collection when the participant stops providing information during the interview. It also enables further exploration of the patient's perspective and experiences through first-person narration of the meaning of the drawing and analysis of the image.<sup>29 40</sup> During the first stage of data collection (participants 1–9), patients received unstructured interviews using open questions<sup>36</sup> such as: 'what is your experience with NDPH?'. A first analysis was performed on the unstructured interviews of participants 1–9. This analysis revealed some relevant topics that required further study, thus making it necessary to include a second stage of data collection. In the second stage (participants 10–19), semistructured interviews were used, based on a question guide (online supplemental material 1) designed to obtain information regarding specific issues of interest.<sup>24 26</sup> The question guide was developed based on the accounts given by the initial nine patients.

All the interviews were taperecorded and transcribed verbatim, recording 1253 min of interviews overall. The

interviews were held at a private room at the hospital by BT, VG-M, DG-A and MG-G, and no third party was present aside.

The researchers also collected field notes on each subject and finally, the patients provided drawings that gave further insight into how they viewed their illness.<sup>23 29 39 40</sup> Thus, when the participant had no more new information to offer, they were asked to draw a picture depicting what it is like to live with NDPH. 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 questions: 'How does your headache feel?' and 'What does the picture represent?' Subsequently, researchers asked the patients to describe the images and content of their drawings and the reasons for their choice of colour, spatial organisation and composition.<sup>40</sup> Could you describe your drawing? Why did you choose those colors? What is the meaning of the drawings and their content (other images, trees, landscapes, etc.)? Why do you organize it this way? Patients' descriptions of their drawings and researcher field notes were part of the analysed data. Sociodemographic and clinical data were also recorded, as well as their scores on the Hospital Anxiety and Depression Scale.<sup>41</sup> There was no drop out.

### Data analysis

The full literal transcription of each of the interviews, the researchers' field notes and the patients' drawings and their descriptions thereof were all collated to perform a qualitative analysis.<sup>24 36</sup> A inductive analysis was performed.<sup>24 26 27 36 42</sup> The analysis consisted of identifying the most descriptive content in order to obtain meaningful units, and subsequently reduce and identify the most common meaningful groups. In this manner, groups of meaningful units were formed (ie, similar points or content that allowed the emergence of the topics that described the study participants' experience).<sup>24 26 36</sup> This process of inductive analysis was performed separately on the unstructured interviews, semistructured interviews and the descriptions of patients' drawings. Also, double and independent coding was performed by two investigators (DP-C, MLC) from the research team. The independent coding consisted of two investigators performing coding separately and without sharing coding files. After completing their coding, they then met to discuss, compare and for a round of refinement. Guillemín's proposal was used to analyse patients' drawings.<sup>40</sup> In this proposal the drawing is analysed together and with the participants' interpretation of their drawing. Both the drawing and the description comprise the data. The researcher is able to draw on the participants' interpretation of their drawing in the analysis.<sup>40</sup> This analysis proposal is divided into two parts; one in which the participant draws and the interviewer asks and analyses the reasons for using certain images, colours and spaces and their meaning through the narratives and descriptions of the participants. Another part, in which the researcher

asks questions to guide the analysis of the drawings, and to take into account the participant's descriptions of drawings, the researchers and the image itself.<sup>40</sup> The questions are related to the production of the image, the image itself and the relationship between the image and audience (online supplemental material 2).<sup>40</sup> In this study, the analysis focused on the verbal descriptions of the meaning of drawings by participants and their relationship to the NDPH, but did not include an analysis of the drawings themselves. Subsequently, joint meetings were held to combine the results of the analysis, to represent the patients' experiences of suffering from NDPH.<sup>24 26 36</sup> In the case of differences in opinion, theme identification was performed based on establishing a consensus among the research team members (see online supplemental material 3, figure 1). Integration and analysis process of qualitative materials. No qualitative software was used to analyse the data. For the analysis, the Excel program was used to organise and share the coding process.

### Rigour

The strategies to ensure trustworthiness consisted of: (1) triangulation (using different data sources, researchers and methods of data collection); (2) auditing of the material obtained from the participants by an external independent researcher who specifically verified the transcribed data, data documentation and management, archival information sheets, interview data tracking forms, field note-taking, the description of the coding tree, patients' quotations, the identification of quotations and themes' descriptions, without participating in the analysis process; (3) prior to the study, the positioning of the researchers was established according to the theoretical framework, their prior experience and their motivation for the research (online supplemental material 4, (4) postinterview patient member checking consisted in offering all participants the opportunity to review the audio or written records. All participants were given an audio copy of the interview; in addition, they were offered the possibility of arranging a session with the researchers to discuss and understand their perspective on the interview process and data collection and to provide further information or nuance to the data collection; however, none of the participants made additional comments and (5) negative or deviant case analysis.<sup>24 26 43</sup>

Written informed consent and permission to record the interviews was obtained from each patient.

### RESULTS

Nineteen patients with NDPH (11 women) were enrolled in this study with a mean age of 45.31 years (SD 10.27) (see online supplemental material 5).

Four main themes were identified: (1) Seeking a diagnosis, (2) Self-medication—minimising pill intake, (3) Trying other options and (4) Medical care, with two subthemes: referrals and lacking continuity of care, and

building the doctor–patient relationship (see [table 1](#) for findings).

A detailed summary of the themes and narratives taken directly from the patients' interviews is shown in [tables 2–5](#) (examples of narratives). These narratives enrich and justify the qualitative results.<sup>33 36 43</sup>

#### Theme: seeking for a diagnosis

The participants described how the sudden appearance of persistent pain without a justified cause is what triggered the search for a diagnosis. Participants were fearful of their pain being provoked by a tumour, and because of the lack of diagnosis, they experienced delays in treatment. The need to confirm the diagnosis meant that patients had to visit many doctors, receiving numerous tests in the search for a response for the pain. For the participants, having a diagnosis is interpreted as a way to give a name to an unknown problem in order to treat it as fast as possible, to eliminate the cause of the pain. A common finding among participants was the experience of duplicity and repetition of tests, as new doctors tend to mistrust the tests performed by the previous doctors. For the participants, this means that the diagnosis is often delayed for years. The participants described how the delay in the diagnosis, and the continual testing was a cause of anxiety and frustration. Consequently, this has an emotional toll, characterised by a lack of motivation, despair and low self-esteem. Because of the delay in diagnosis, the participants related how the emergency services are often used as a 'short cut'. A rapid neurologist assessment is sought by patients, to obtain an early diagnosis, and a fast referral to specialist consultations (see [table 2](#)).

#### Theme: self-medication—minimising pill intake

The participants perceived that they had not received an effective treatment to provide long lasting relief from pain. They expected a list of effective treatments but felt that the choice of drugs to be used was being improvised, 'trying things out to see what works'. The prescribed pain medication involved a wide variety of specific pain killers, and non-specific drugs (ie, for the treatment of anxiety, insomnia, depression). For the participants, adherence to the prescribed treatment, meant having to use a great number of drugs, for a long period (years), without a clear effect. This cast many doubts and a great deal of uncertainty regarding the ability to reduce this medication in the future or if this meant they were to become chronic consumers. The study participants often discontinued treatment as they felt it was not justified to take drugs that fail to work, and because of the presence of side effects (such as nausea, vomiting, drowsiness and disorientation). Not following the treatment was sometimes accompanied by episodes of pain, which the patients must endure. Participants acknowledged that enduring the pain could help them to not need medication. Some patients reported not completely giving up their medication, rather they chose to take their treatment with a certain 'flexibility'. This means modifying the



**Table 1** Findings

Themes	Common meaning groups
Seeking a diagnosis	<ol style="list-style-type: none"> <li>1. The reason for seeking help</li> <li>2. Looking for an answer</li> <li>3. The meaning of the diagnosis</li> <li>4. Duplication and repetition of diagnostic tests</li> <li>5. Delayed diagnosis</li> <li>6. Reaction to delayed diagnosis</li> <li>7. ER as a shortcut to see a specialist</li> </ol>
Self-medication—minimising pill intake	<ol style="list-style-type: none"> <li>8. Ineffective treatment</li> <li>9. Trial and error approach to treatment</li> <li>10. Polypharmacology</li> <li>11. Prolonged drug use</li> <li>12. Discontinuing treatment</li> <li>13. Enduring the pain</li> <li>14. Flexible use of prescribed treatment</li> </ol>
Trying other non-pharmacological options	<ol style="list-style-type: none"> <li>15. Trying other therapeutic options</li> <li>16. Second choice therapy</li> <li>17. Ineffectiveness of other therapies</li> <li>18. Unexpected positive effects of other therapies</li> </ol>
Medical care	<p>Subtheme: Referrals and lacking continuity of care</p> <ol style="list-style-type: none"> <li>19 Referral among medical specialists.</li> <li>20 Referral criteria</li> <li>21 Referral to a psychiatrist</li> </ol> <p>Subtheme: Building the doctor–patient relationship</p> <ol style="list-style-type: none"> <li>22 The basis of the doctor–patient relationship</li> <li>23 Characteristics of the doctor–patient relationship</li> <li>24 Things a doctor should avoid</li> <li>25 Consequences of a poor doctor–patient relationship</li> </ol>

ER, Emergency room.

pharmacological guideline based on their own personal criteria; travelling somewhere, the appearance of pain episodes or facing a heavy workload. None of the participants reported the simultaneous use of other substances such as alcohol, drugs or non-prescribed medications while under treatment (see [table 3](#)).

### Theme: trying other non-pharmacological options

After confirming that the prescribed treatment was unable to eliminate the pain, participants acknowledged trying other non-pharmacological therapies, which included a great diversity of therapies coming from traditional medicine, or treatments from other medical disciplines such as: psychology, psychiatry, psychotherapy, Reiki, acupuncture, yoga and/or Pilates. In this group, participants included everything that is not pharmacological therapy. These therapies are used as a second option, when the pharmacological treatment has failed or has not met their expectations. Thus, this is never the first option, but rather the choice that is made after pain relief has failed, triggering the need to try other non-pharmacological therapies. Over time, after trying these therapies, participants perceive these as being ineffective. Two participants noted that these therapies did not decrease the pain, however, they did decrease the number of drugs needed to control the pain, helping them to find meaning in

their pain, and to cope with this new stage in their life (see [table 4](#)).

### Theme: medical care

This theme is conformed of two subthemes. In relation to the subtheme ‘Referrals and lacking continuity of care’ participants narrate aspects of the referral process and how it affects continuity of care. In the subtheme ‘Building the doctor–patient relationship’ participants describe the elements that help or hinder building and establishing the relationship with the doctor.

#### Referrals and lacking continuity of care

The participants described how they visit many doctors and undergo referral between specialists, for example, from the primary care physician to the neurology specialist; or from the orthopaedic surgeon to the neurologist. Referrals are perceived as being necessary because a more accurate diagnosis is sought. However, for the participants, visiting a new doctor means starting the whole process from scratch, receiving diagnostic tests and testing the most suitable drug. Participants do not perceive a continuity of care, rather, it is perceived as a process of going back and forth between different doctors. In addition, participants described how, before making a referral to other specialists they consider more

**Table 2** Examples of narratives of patients with NDPH**Theme: Seeking a diagnosis**

Common meaning groups	Narratives
1 The reason for seeking help	Sudden and persistent pain: 'It's normal to have a headache at some point. And it's normal for there to be a cause for it, however, like this? Suddenly, and every day, at all times, always? I went to the doctor and began seeking help.' (P5). Fear for the cause of pain: 'I was scared, that there may be a tumor, for time to go by and not be able to treat it on time. The sooner you know what is happening to you, the sooner you are given treatment to cure it. That's why I wanted to know the diagnosis.' (P2)
2 Looking for an answer	Using all possible means: 'I was hospitalized for three days and they did an electrocardiogram, x-rays, NMRs, blood tests... Everything you could imagine, with the hope that at some point they would find something.' (P3)
3 The meaning of the diagnosis	The name, the label: 'Knowing the name of what I have, knowing that the doctors know what to treat, that they aren't going to go round and round anymore' (P16)
4 Duplication and repetition of the diagnosis tests	Starting the tests again: 'When I got to a new doctor, the process was repeated once again, doubts and mistrust for all the tests previously performed. In the end, they ask for all the same tests again. The new doctor wants to decide with his own data and his tests,... time wasted.' P18)
5 Delayed diagnosis	Diagnostic delay: 'They should have sent me to the neurologist for the diagnosis a long time ago. And stop doing so many tests only to obtain the same results. All these years with pain has been unwarranted and unnecessary.' (P4)
6 Reaction to delayed diagnosis	Frustration when new diagnostic tests are requested: 'They told me that they didn't see anything and I left in despair. It was frustrating, I couldn't take it any longer. They had to repeat more exams and I had to wait longer. All day long with pain and I still had no treatment.' (P5). Feeling discouraged due to the lack of answers: 'Not knowing what I have after so many tests makes me feel really bad, like I am worthless. For them not to know what I have after seven years, and when the pain is increasing, it lowers your morale. You don't feel like doing anything.' (P5)
7 ER as a shortcut to see a specialist	Health care shortcut: 'For me, going to the emergency room was a way of finding a faster response. However, it was my doctor who sent me. The tests were taking too long and I wanted the opinion of a neurologist as soon as possible. In the emergency department, I was seen by the neurologist on duty' (P2)

Theme: seeking a diagnosis.

ER, Emergency room; NDPH, new daily persistent headache.

appropriate for their disease, all of the doctors wish to complete all possible diagnostic tests and treatments (see [table 5](#)).

This is perceived as a barrier, as it sometimes delays referral to other specialists, such as the neurologist. Therefore, referral to a neurologist is not a first option. This leads to feelings of frustration and despair. Sometimes, when a diagnostic test fails to provide an answer, patients are referred to a psychiatrist, assuming a mental cause for the symptoms. However, in most cases, the psychiatrist is unable to help. Furthermore, the participants described how referral to a psychiatrist comes after many years of treatment. In these cases, the study participants felt that the problem is because of their way of being, or because of something they have done. Thus, the participants failed to understand why they should see a psychiatrist, as they feel that they do not need this type of treatment, or that it is not suited to their problem.

### Building the doctor–patient relationship

The participants explained that the main reason to visit the doctor was not only to receive effective treatment, they also sought an answer (diagnosis) to explain the pain, and it was very important for them to find medical support to cope with the illness. According to the participants, in the doctor–patient relationship it is important for the doctor to be approachable and friendly, respectful, sincere and honest. In addition, the doctor should support and protect the patient, listen to the patient and let the patient talk, treating the person without being in a rush, taking the patient seriously and remembering the patient's name. Participants valued the doctors who displayed interest in each individual case, seeking answers despite the difficulties, providing the patients with options and allowing them to participate, without forgetting them, accompanying patients through their pain and remaining at their side throughout the process. The fact that some doctors appear to give up from the very beginning or read their medical records with no idea what to do was perceived as a source of disappointment and distress.

**Table 3** Examples of narratives of patients with NDPH

**Theme: self-medication—minimising pill intake**

Common meaning groups	Narratives
8 Ineffective treatment	Persistence of pain: ‘After so many years, they still don’t have a drug to get rid of the pain. I know that I am going to be in pain until I die.’(P10)
9 Trial and error approach to treatment	Trial and error: ‘The neurologist told me that this headache is trial and error, that the treatment that works for one person, might not work for me, so she keeps trying. When I go to a new doctor, he only studies the list of treatments that I have received, and if there is one that I have not tried already, they try with that one.’(P18)
10 Polypharmacology	Multidrug use: ‘Considering all the different treatments, these years I have had between 35 and 40 drugs prescribed in total, sleeping pills, pills for depression, muscle relaxants, 19 years are a lot of years’ (P1)
11 Prolonged drug use	For the rest of my life : ‘Am I going to have to take the medication all my life? Am I going to be able to decrease the pills gradually, as I get better? I am going to have to take them my whole life and these are drugs are quite strong.’ P18)
12 Discontinuing treatment	Why continue pharmacological treatment?: ‘If it doesn’t take away my pain, and on top of it all, it makes me feel like vomiting, why should I take medication? I prefer not to take anything.’ (P2), ‘He gave me some pills, which left me feeling almost as if I weren’t myself, as if I wasn’t a person. What I want is to be myself, but without pain, and without having to be drugged up all the time and lying around at home.’(P5)
13 Enduring the pain	Why endure the pain?: ‘I try not to take the treatment and I try to withstand the pain, because I think that one day I will learn to manage the pain and not depend so much on a pill.’ P17)

Continued

**Table 3** Continued

**Theme: self-medication—minimising pill intake**

Common meaning groups	Narratives
14 Flexible use of prescribed treatment	Increased flexibility in the medication regimen: ‘It depends on the activity that I have had that day, and if I have pain. If I have a lot of work, I increase the drugs I take because I know that the pain will worsen. If it is a very intense pain, I don’t take anything, and I try to withstand it.’(P1), ‘The medication is always according to my needs, one day I need it, one day I don’t, it depends on how I feel. It’s important to be flexible. I try to minimize the number of pills I take.’ (P3)

Theme: self-medication—minimising pill intake  
NDPH, new daily persistent headache.

The participants felt that a doctor should never question the patient and should avoid expressing disbelief concerning the reality of the patient’s pain or asking questions that doubt the patient’s experience. These are attitudes that were perceived by the study participants, when they acknowledged that they were not following the prescribed treatment rigorously. Thus, doctors tend to prescribe many drugs, even if they have been prescribed in previous treatments and were ineffective. Ultimately, the participants in this study felt that they are a ‘mere number’. For the study participants, the doctors’ lack of interest worsens the feelings of pain and leads to feelings of despair regarding whether they will be able to find a way out of the pain.

## DISCUSSION

Our findings, obtained from participants attending two headache units in Spain, show that during the search for a diagnosis, participants undergo a multitude of tests and diagnostic delays. In addition, they minimise the use of the medication prescribed by the physician or modify the regimen according to their interests. Participants try other non-pharmacological measures which fail to eliminate their pain, although they find unexpected positive effects. Finally, participants described how physician referral broke the continuity of care and described the facilitators and barriers they perceived in the relationship with physicians.

### Seeking for a diagnosis

Our results show how the diagnostic delay, multiple testing and the performance of multiple tests do not meet the participants’ expectations. Thus, the use of multiple diagnostic tests, and multiple drugs to control pain, and the selection of the most suitable drug for each patient, is standard medical practice.<sup>3 44</sup> Bösner *et al*<sup>44</sup> reported

**Table 4** Examples of narratives of patients with NDPH**Theme: Trying other non-pharmacological options**

Common meaning groups	Narratives
15 Trying other therapeutic options	Other non pharmacological options: 'I have tried everything, acupuncture, diets, chiropractors, 5000 types of naturopaths, eastern therapies, psychology ... I'm only missing witch doctors.' (P1)
16 Second choice therapy	Second choice therapy: 'They were never my first choice. It was when the drugs failed that I considered them as a viable option. However, an option after drugs, as a last resort.' (P5)
17 Ineffectiveness of other therapies	Other therapies are ineffective for eliminating pain: 'I have tried acupuncture and homeopathy and these have not worked, the headache did not go away at all. I wasted my time.' (P11)
18 Unexpected positive effects of other therapies	Unexpected positive effects of other therapies: 'Personally, the therapy has not helped me with my headaches, but it has provided me with my own personal resources, it improved my self-esteem, it helped me to care for myself better and to know how to set limits. The pain didn't change, what changed was myself, and everything improved.' (P11)

Theme: trying other non-pharmacological options.  
 NDPH, new daily persistent headache.

that the central meaning of the long-term relationship with headache patients from the doctors' perspective, was that 'what' the patient was saying was not as relevant as 'how' this occurred. Moreover, doctors often have to deal with diagnostic uncertainty. To handle this uncertainty, doctors use therapeutic trials to establish a diagnosis.<sup>44</sup> In the study by Bösner *et al*<sup>44</sup> the patient's response to therapy is helpful in reducing uncertainty, as it reduces the likelihood of any other underlying disease or another type of headache disorder. The dissatisfaction of our participants with the diagnostic process can be explained by the fact that both doctors and patients assume a biomedical approach to the disease and its symptoms.<sup>45</sup> The participants expect medicine to identify the cause and provide the 'right' treatment. This expectation is rooted in the beliefs that medicine is an exact science, and there is a cause, and this cause is organic. Furthermore, based on the participants' narratives, it could be interpreted that doctors act on the assumption that there is a cause, most of which is organic, which explains the multiplication and duplication of tests. The fact that NDPH is a recent, chronic entity, producing continuous pain and with no explanation of its etiopathogenesis, accentuates the request for diagnostic tests.<sup>46</sup>

In relation to visiting multiple physicians in search of a diagnosis, the participants may have presented a behaviour known as 'doctor shopping'.<sup>47 48</sup> This term refers to the behaviour of patients characterised by the pilgrimage from one doctor to another, with the aim of obtaining drug prescriptions (addiction),<sup>49</sup> to be diagnosed with a certain disease, or because of dissatisfaction with the professional care received.<sup>47</sup> Certainly, based on their narratives, our participants present characteristics that are compatible with doctor-shoppers, such as presenting intense pain, treatment including analgesic opioids and other coadjuvant drugs, as well as dissatisfaction with medical care.<sup>47</sup> However, the authors believe that this phenomenon is not marked in Spain, because most healthcare comes from the public health system. This means that in order to visit a specialist, the patient

must first be referred by another physician who justifies the need for the referral. This pilgrimage could be limited in the public health system, which is where the participants in our study were recruited from.

The presence of unexplained chronic pain and its management and communication is relevant for professionals.<sup>50 51</sup> The International Association for the Study of Pain (IASP) defined chronic pain as pain that persists or recurs for more than 3 months.<sup>52</sup> In addition, in chronic pain syndromes, pain may be the only complaint or a chief complaint and requires special treatment and care.<sup>52</sup> In conditions such as nonspecific low back pain,<sup>52</sup> and chronic primary (idiopathic) headache,<sup>53</sup> chronic pain can be conceived of as a disease in its own right, falling under the subgroup chronic primary pain in the International Classification of Diseases-11.<sup>52 53</sup> From a biomedical perspective, where there is a cause that explains the symptoms and disease, NDPH, like other conditions (low back pain) may hinder communication with patients suffering from unexplained chronic pain.<sup>50 51</sup> Hintz and Scott<sup>54</sup> reported that chronic unexplained pain is a condition with a high degree of uncertainty and ambiguity that causes changes in the discourse (way of communicating, and contents of the communication) between doctor and patient, generating barriers in the therapeutic relationship between both parties. In this communication, the dialogue between doctor and patient must reach a common point in which the doctor's dialogue based on objectifiable dimensions must match the patient's dialogue based on experiential contents.<sup>50 55 56</sup> Olde *et al*<sup>57</sup> describe doctors' difficulty in dealing with medically unexplained symptoms such as some types of pain. These authors emphasise the need to build a doctor-patient relationship based on a model of mutual alliance, characterised by ritual care (regular physical examination, periodic visits) with the approval of the patient and the physician.<sup>57</sup>



**Table 5** Examples of narratives of patients with NDPH**Theme: Medical care****Subtheme: Referrals and lacking continuity of care**

Groups of common meaning	Narratives
19 referral among medical specialists.	Referrals among doctors: 'Now I am with the neurologist. But everything began with the orthopedic surgeon, because I had something in my back and I was thinking of having an operation. Beforehand, he sent me to the physiatrist to try and strengthen my back. But, then the physiatrist sent me to the neurosurgeon because she saw something strange in my x-ray. After the NMR, the neurosurgeon decided to send me to the neurologist.' (P16). No continuity of care: 'I went to another center and a different doctor saw me. It's like starting all over again, they ask you the same questions again because they don't know you. They would give me a treatment and at the next appointment it was another person, and back to the beginning. Thus, until the next referral to another physician.' (P17)
20 referral criteria	Need for referral: 'After almost a year of treatments, and trying everything, the doctor told me that neurologically he wasn't achieving anything and that he would have to continue by consulting other specialists, because he didn't know what to do.' (P3), 'I am referred when they don't know what else to do. That's what they all do.' (P12) Referral to a neurologist?: 'The doctor has tried a thousand things, to finally end up saying that he didn't know what I had and sending me to the neurologist for a headache, shouldn't that be the first option?' (P17)
21 referral to a psychiatrist	Mental cause: 'He sent me to the psychiatrist, because he didn't see anything in the tests... So it had to be mental. But the psychiatrist didn't know what to do.' (P5), 'I was derived because there wasn't a doctor to certify that I had an illness with a proper name. So, because that didn't exist because nothing was found in the tests, they assumed that it was something mental of my own, something I had to resolve myself.' (P1) The pain and the patient's way of being: 'Now it turns out that I am the problem, I am the cause of this... as if I like having a headache...' (P1) No reasons to go to the psychiatrist: '... I admit that I felt somewhat angry when they told me that it was something psychiatric. How can that be? If it feels very real and physical' (P1), 'I went to the psychiatrist, we were 10 or 15 people, completely different. It had nothing to do with my problem.' (P17)

**Subtheme: Building the doctor–patient relationship**

22 The basis of the doctor–patient relationship	The reason for the relation with the doctor: 'The first thing that I ask him is to take away the pain, for it to be effective, that's why I come...' (P1), 'They must listen, but above all, they must identify the problem and resolve it.' (P16). Support from the doctor 'What I sought was the kind of doctor that made things click for me, someone who was able to show me another way of seeing things and managing it.' (P1)
23 Characteristics of the doctor–patient relationship	Characteristics of the doctor–patient relationship: 'Sincerity is vital, although there are no solutions. For the doctor to be able to tell me that there are no alternatives, but to continue searching.' (P3), 'It provides me with peace of mind, using all the time I need to understand it, not to be in a rush.' (P17), 'For them to call you by your name is a small detail which makes a difference.' (P17). Characteristics of an approachable and friendly doctor: 'The doctor must be close, must be interested in your case. You can tell when you see that he or she is concerned, when no explanation is found and still they find it' (P2), 'I only ask the doctors to not forget about me.' (P5), 'It's essential for the same doctor to do a follow-up, that makes you trust them more. When you have this kind of pain, this is very important.' (P12).
24 Things a doctor should avoid	Giving up too soon: 'You realize that he has already given up. He doesn't say not to come, but they tell you that they can't guarantee that they can help. They don't know what else to try and so they send you to another doctor. I feel like they have given up, I am disappointed.' (P18), 'They are the ones who know and if they don't know what to do, what am I supposed to do? It's as if they abandon you, they leave you alone with your pain.' (P19). Not believing the patient: 'It feels like they don't take you seriously with your pain, because it's something that you can't see. To say that you have pain is like saying that you don't have anything.' (P12). 'They don't believe that such a strong pain exists for so long and that you don't take anything. If you don't take any medicine, they think that you don't have such a strong pain.' (P9).

Continued

Table 5 Continued

## Theme: Medical care

## Subtheme: Referrals and lacking continuity of care

Groups of common meaning	Narratives
25 Consequences of a poor doctor–patient relationship	<p>Repeating ineffective medication: ‘They send you six treatments, half of which are repeated, medication that hasn’t been helpful for anything, and all because they don’t listen to you.’ (P17).</p> <p>The patient is a number: ‘You realize that they aren’t taking any notice of you, because you stay quiet in the middle of the conversation and they don’t even realize. We are a number after all, and when you leave, another number comes in, and they don’t even recognize a person’s face or the name.’ (P17).</p> <p>No way out: ‘If the doctor who you depend on isn’t interested, how am I going to control all of this, he doesn’t even realize that he is my only hope and my only way out of this. If he isn’t interested, where should I turn for help...? (P17)</p>

Theme: medical care.

NDPH, new daily persistent headache.

## Self-medication: minimising pill intake

Our results show that participants are not satisfied with the treatment received. Previous studies in chronic migraine<sup>58 59</sup> reported that drug prescription is met with distrust and scepticism. According to these studies, patients fail to believe that they will ever be pain free and, to them, for a treatment to be successful, it should reduce pain to levels that enable them to live a ‘normal’ life.<sup>58 59</sup> The dissatisfaction reported by our participants could be related to their expectations based on their beliefs. The health belief model proposes that health behaviours are shaped by perceptions of disease susceptibility, severity, barriers to health practices, benefits, self-efficacy and cues to action.<sup>60 61</sup> As the health belief model explains<sup>60 61</sup> beliefs lead to actions (eg, believing that taking too many medications or for too long is dangerous can lead to discontinuing prescribed treatment or enduring pain without medication). Willis in his study on Medication nonadherence in arthritis using the Health Belief Model reported that pain was the most commonly experienced barrier to medication adherence.<sup>60</sup> Also, patients included in Willis’ study noted that although they knew the medications were necessary, they often questioned the benefits of their prescriptions because of their levels of pain and stiffness.<sup>60</sup> This author concludes by noting that pain was the common denominator of patients’ perceived barriers to medication adherence, and how patients’ satisfaction with the level of pain suffered and their expected level of pain (with medication treatment) shaped their attitude towards medication prescribing.<sup>60</sup> The authors, based on the narratives of our participants, believe that doctors seem to reinforce the idea that there is an organic cause that causes them to multiply and duplicate tests in search of a diagnosis, rather than address patients’ beliefs and expectations. Our study reveals that some patients endure episodes of pain in the hope of reducing their consumption of painkillers. Our findings could be explained by the patients’ need to regain control over their lives. Rutberg *et al*<sup>62</sup> reported that the

use of symptomatic treatment in migraine patients is associated with a perceived loss of power and a lack of control over their life. In contrast, Jonsson *et al*<sup>63</sup> reported that patients with migraine and tension-type headache viewed medication as the only effective solution making symptomatic treatment indispensable. The discontinuation of symptomatic treatment may be due to factors such as lack of knowledge, role responsibilities, adverse effects, inefficiency of symptomatic treatment and fear for long-term effects.<sup>58 63 64</sup> Previous qualitative studies<sup>58 62</sup> have found that migraine patients generally do not want to use more medication than what is absolutely necessary, as they are afraid that long-term use can reduce the effect of the medication, negatively affecting them or increasing the risk of them becoming addicted to the medication. Our results display how some NDPH patients applied a ‘flexible solution’ concerning their use of medication prescribed by the physician. Our participants do not report situations of self-medication, understood as the inclusion and consumption of new drugs or substances (drugs or alcohol) without prescription or medical assessment. Unlike other conditions such as cluster headache, where patients report how they need to consume different types of substances or drugs together with the prescribed treatment to find an analgesic effect.<sup>65</sup> Previous qualitative studies<sup>62–64</sup> with migraine patients highlighted a similar ‘flexible’ use of medication by patients. Thus, migraine patients negotiated their use of medication, deliberating over what kind of treatment they needed to use and whether to start treating a migraine attack at once, or whether it was possible to wait.<sup>62</sup> Also, patients decide the type and dosage of medication most likely to manage the headache optimally, and use personal symptom profiles and contextual cues to decide which type of medication to take.<sup>64</sup>

## Trying other non-pharmacological options

Our results show two groups of treatments, pharmacological treatments as the first option and the non-pharmacological

treatment group. Non-pharmacological therapies were used by the study participants when medication failed to work. This group includes any non-pharmacological treatment, regardless of whether they come from other health science disciplines (such as physiotherapy or psychology), from/and complementary therapies (used in addition to conventional treatments) and/or from alternative therapies (used instead of conventional treatment) such as acupuncture or yoga. Previous qualitative studies<sup>59 63 64</sup> showed similar behaviour in patients with migraine and headache. In those studies<sup>59 63 64</sup> patients reported using herbal remedies, physiotherapy, yoga, massage, acupuncture, osteopathy, homoeopathic remedies, reflexology, body awareness training, naturopaths and diets, simultaneously or instead of prescribed medication. Moreover, our results agree with those reported by Jonsson *et al.*<sup>63</sup> Thus, headache patients tried numerous non-pharmacological strategies, which failed to work and as a result, patients returned to their use of medication. For the authors of this work it is striking that from the perspective of the participants the therapeutic options are divided in this manner, as it shows the great relevance they give to medication. The relevance of medication in patients with headache also appears in the qualitative study by Peters *et al.*<sup>59</sup> on migraine and chronic daily headache, where it has its own category, separate from the alternative therapies category. In addition, it is striking that our participants did not mention anything about the scientific demonstration of some of these therapies, for example, by using criteria such as evidence-based medicine.<sup>66</sup> The presence of numerous studies and clinical trials on the effect and efficacy of non-pharmacological therapies for pain (whether or not they belong to complementary or alternative therapies) supports the need to have an updated and continuous knowledge about these therapies.<sup>67–70</sup> In this regard, professionals should play a relevant role in the dissemination of effective therapies against headache and chronic pain.<sup>70</sup> Finally, our results reveal how unexpected results were obtained. Some non-pharmacological treatments did not eliminate the pain although they helped the participants to cope with the pain in their lives. Wells *et al.*<sup>70</sup> reported that in the case of mindfulness, it will not ‘cure’ migraine; however, it can be an important tool as part of a comprehensive treatment approach to help patients ‘mindfully’ engage in valued life activities.

### Medical care

Our findings revealed that referral to headache specialists took time. Our results agree with those of Bönsner *et al.*<sup>44</sup> who reported how medical specialists were normally only consulted if the therapy initiated by a doctor did not show any signs of success and/or symptoms did not resolve. Moreover, in Spain, the diagnosis and management of NDPH by neurologists may be delayed by the structure of healthcare.<sup>15</sup> When experiencing a headache, the patient first goes to the primary care physician and is subsequently referred to a medical specialist. The neurologist may be

one of the options, because the NDPH may not have been identified and the patient may present clinical manifestations that can be confused with other disorders that require other specialists such as anaesthesiologists, orthopedists, etc.<sup>17</sup> Our patients described the importance of the effectiveness of medical treatment and counting on doctors’ personal support. Rutberg *et al.*<sup>62</sup> found that doctors influenced the patients’ own acceptance of being afflicted with migraine, by either taking them seriously or by causing them to feel mistrusted or dismissed. This may be because, when migraine patients sense that they are trusted and understood, they find it easier to accept their disorder and to handle the emotions associated with their affliction.<sup>58</sup> Palacios-Ceña *et al.*<sup>58</sup> reported how chronic headache patients expect sincerity, support and for their doctors to become involved in their disease. Moreover, they feel isolated when having to deal with their pain and they need to feel their doctor’s support, whereby their disease must involve both parties.<sup>58</sup> Also, all patients identify situations that hinder the doctor–patient relationship, such as: when a doctor prescribes a treatment that has already been used unsuccessfully in the past, when inefficient treatments are maintained for a long time, when migraine is viewed as a minor symptom or affliction.<sup>58</sup> The authors of the present study believe that NDPH is an invisible illness, which could explain some behaviours displayed by doctors. Palacios-Ceña *et al.*<sup>58</sup> reported that chronic migraine is experienced as an invisible process, and the path leading to the diagnosis can be long and tortuous, due to the doctor’s mistrust and scepticism. Also, the active participation of the patient in their care, an effective communication and partnership can facilitate medical care, effective case management and an efficient use of resources.<sup>71</sup> Patient-centredness is achieved in part by understanding patients’ experiences with illness and disease as well as striving to achieve a more holistic understanding of the patient.<sup>71</sup>

Our results identify key points that can help in the management of NDPH. Among other findings, this study highlights the importance of listening to and identifying the beliefs and expectations of patients suffering from NDPH, since these can hinder adherence to treatment and favour its ‘flexible’ use. It is also necessary for the doctor to explain and help the patient understand the diagnostic process, the reasons and justification for the request for tests, and expected results to avoid dissatisfaction or frustration. It is necessary to build a supportive and trusting relationship between physicians and patients. The physician’s support is relevant for the patient, and through this relationship the physician can help patients to know and understand their treatment and other therapeutic options (pharmacological and non-pharmacological) and choose the best option to meet their expectations. In short, it is necessary for healthcare professionals to deepen their knowledge and understanding of the experience of people suffering from NDPH.

## Strengths and limitations

Among the strengths of this study, to the best of our knowledge, this is the first study to describe the experiences of NDPH patients regarding the diagnostic process, treatment and medical care using a qualitative research approach. Also, non-structured and semistructured interviews and descriptions of patients' drawings were used to collect qualitative data as they enable the patient's experiences with NDPH (chronic pain) to be analysed. It is important to note that this study has certain constraints on the generalisability of findings, which limit the extrapolation of our results to the entire population of patients with NDPH. Although the results cannot be extrapolated to the entire population, they can help physicians better understand the impact of the NDPH and the patients' perspectives regarding the diagnostic process, treatment, use and follow-up of the treatment and relationship with the physician.

## CONCLUSIONS

In conclusion, our results provide insight on how diagnoses, treatment and medical care are experienced by a group of Spanish NDPH patients, which may be helpful in managing NDPH. Patients require answers related to their diagnosis and the treatment of their pain. The patients' implication is necessary in order to make joint decisions with their doctor, who should provide information and discuss the referral process. This must be viewed as an important factor in the management strategy for NDPH. It would be interesting to further analyse the NDPH patients' perspective regarding their relationship with doctors.

### Author affiliations

<sup>1</sup>Department of Physical Therapy, Occupational Therapy, Rehabilitation and Physical Medicine, Universidad Rey Juan Carlos, Alcorcón/Madrid, Spain

<sup>2</sup>Research Group of Humanities and Qualitative Research in Health Science, Universidad Rey Juan Carlos, Alcorcón/ Madrid, Spain

<sup>3</sup>Department of Neurology, Hospital Clínico Universitario de Valladolid, Valladolid, Spain

<sup>4</sup>Department of Neurology, Hospital Clínico San Carlos. Instituto de Investigación Sanitaria San Carlos, Madrid, Spain

<sup>5</sup>Department of Anesthesiology, Hospital General de Segovia, Segovia, Spain

<sup>6</sup>Department of Neurology, Hospital Clínico San Carlos, Department of Medicine, School of Medicine, Universidad Complutense de Madrid, Madrid, Spain

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### ORCID iDs

Domingo Palacios-Ceña <http://orcid.org/0000-0003-0669-6339>

Blanca Talavera <http://orcid.org/0000-0001-7692-0186>

David Garcia-Azorin <http://orcid.org/0000-0002-3132-1064>

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