**Perceptions, experiences and understandings of cluster headache among GPs and neurologists: a qualitative study**

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**ABSTRACT**

**Background**

Cluster headache (CH) is a severe primary headache with a similar prevalence to that of multiple sclerosis. CH is characterised by unilateral trigeminal distribution of pain, ipsilateral cranial autonomic features and a tendency to circadian and circannual periodicity.

**Aim**

This is the first study to explore perceptions, experiences and understanding of CH among GPs and neurologists.

**Design and setting**

Qualitative interview study in primary care surgeries and neurology departments in the North of England, UK

**Method**

Sixteen semi-structured interviews were conducted with GPs (*n*=8) and neurologists (*n*=8), recorded and transcribed. A thematic analysis was applied to the data set.

**Results**

Four main themes were identified following thematic analysis: (1) Challenges with the CH diagnosis; (2) Impact of CH; (3) Challenges with treatment; (4) Appropriateness of referrals to secondary care. Clinicians recognised the delays in the diagnosis of CH, misdiagnosis and mismanagement and were aware of the potential impact CH can have on patients’ mental health and ability to remain in employment. Findings highlighted tensions between primary and secondary care around the cost of medication and the remit of prescribing treatment regimes. Patients’ anxiety, their need for reassurance and their insistence to see a specialist are some of the reasons for referrals.

**Conclusion**

Clinicians acknowledged delays in diagnosis, misdiagnosis and mismanagement of CH. The responsibility of prescribing causes ongoing tensions between primary and secondary care.

Clear referral and management pathways for primary headaches are required to improve patient outcome and healthcare cost.

**Keywords:** diagnostic delay, family practice, secondary care, doctor-to-doctor communication, general practice, primary care, prescribing

**INTRODUCTION**

Presentations with headache represent 4% of consultations in primary care and 25% of new referrals to neurological services.1, 2 Cluster headache (CH), a severe primary headache, which presents in both episodic and chronic forms, is often misdiagnosed as migraine and, as a consequence, is often mismanaged (see table 1).3, 4

|  |  |  |
| --- | --- | --- |
| Clinical feature | CH | Migraine |
| Distribution of pain | Orbital, supraorbital and/or temporal pain4 | Usually frontotemporal but can affect any part of the cranium4 |
| Untreated attack duration  | 15min-3 hours4 | 4-72 hours4 |
| Severity of pain | Severe or very severe 4 | Moderate or severe4 |
| Strict unilaterality of pain | Yes4 | No4 |
| Restlessness | Yes4 | No4 |
| Cranial autonomic features | 94% of patientsProminent, unilateral, consistently present from one attack to other5 | 56% of patientsLess prominent, bilateral, and inconsistently present from one attack to another5 |
| Male:female sex ratio | 2-3/110 | 1/312 |
| Temporal pattern | Episodic CH:At least two cluster periods lasting 7 days to 1 year, separated by pain free periods lasting 1 year or more10Chronic CH:Attacks occur without remissions for more than 1 year, or with remissions lasting less than 3 months4 | Episodic migraine: Frequency often 1–2/month but variable from 1/year to 2/week or more12Chronic migraine: Episodicity lost: headache on ≥15 days/ month, having migrainous features on ≥8 days/month12 |
| Aggravation by routine physical activity | No4 | Yes4 |
| Association with smoking | Yes10 | No13 |
| Triggers | Alcohol,10 sleep14 | Alcohol,14 sleep deprivation,15 weather changes,16 menstrual cycle16  |

*Table 1. Clinical features of CH versus migraine*

CH is characterised by recurrent attacks with strictly unilateral trigeminal distribution of pain, ipsilateral cranial autonomic features and tendency to circadian and circannual occurrence.4 The pain during a CH attack is severe to excruciating and associated with restless behaviour.4 Such attacks can last from 15 minutes to 3 hours, whereas untreated migraine attacks typically last from 4 hours to 72 hours.4 Although all primary headache disorders can have associated cranial autonomic features, the intensity and frequency are more predominant in CH.5 CH is commonly referred to as ‘suicide headache’, as 64% of patients have passive suicidal ideation.6 Patients with CH experience difficulties at work and often require sick leave.7 In many cases patients’ needs are unmet.3,8 CH management is unique amongst primary headaches. Due to short lived attacks, CH is treated with sumatriptan subcutaneous injections, nasal triptans and high flow oxygen9, 10 Short periods of CH are managed with short-term prevention with corticosteroids or greater occipital nerve blocks.9 The preventative treatment of CH includes: verapamil, topiramate, lithium and melatonin.11 Although CH is not widely recognised, its prevalence (1/1000)17 is similar to that of other neurological conditions such as multiple sclerosis (0.9/1000)18 and Parkinson’s disease (1-3/1000).19 The majority of headache presentations are managed in primary care and only 2-3% are referred to specialist services in neurology.1Although there is a robust biomedical evidence base on CH,20-23 there is a significant gap in our understanding of how healthcare professionals understand CH and experience this debilitating primary headache in their own clinical practices. To date, there is limited qualitative research on CH and such research available focussed on secondary care or on the gendered dimension of CH.31,24, 25,26 Our study, the *Cluster Headache: Impact and Perception Study* (CHIPS), concentrates on the experiences among the three main CH stakeholders: patients, GPs and neurologists.27 In this paper, we present our findings among healthcare professionals. The aim of this study is to explore the perceptions, experiences and understandings of CH among GPs and neurologists.

*How this fits in*

Clinicians’ perspectives and experiences of CH were never before explored in a qualitative study. This study identifies the importance of GPs’ and neurologists’ understanding of CH and the dynamics and challenges of the relationship between primary and secondary care. CH is a condition poorly recognised in primary care, patients face long delays to receive a correct diagnosis, misdiagnosis and consequently also mismanagement currently abound. Awareness of the disease severity and associated comorbidities, such as depression and high risk of suicidality, should be raised among GPs and healthcare professionals working in primary care settings.

**METHOD**

**Study design**

A qualitative research approach using semi-structured interviews was used to explore the perceptions, experiences and understanding of CH among GPs and neurologists. This study was undertaken by an multidisciplinary research team comprised of a medical sociologist (LD), a medical student (YM) and neurologists working in different medical settings (AB, FA, KP, PJG). As conventional in applied health service research, we used both an emic (‘insider’) and etic (‘outsider’) perspective in preparing the study documents and in our analysis.34 Our multidisciplinary research team consist of ‘outsiders (sociologist, medical student and a neurologist working in Belgium) and ‘insiders’ (neurologists working in the NHS, like the neurologists who participated in the CHIPS study).

**Setting and data collection**

GPs and neurologists were recruited from several primary and secondary care trusts in the North of England, UK. GPs and neurologists received a personalised email with an invitation to participate in the interview. Face-to-face interviews were the preferred option, but telephone interviews were considered if that was the healthcare professional’s preference.28 All interviews were conducted by a medical sociologist (LD). An interview topic guide was used, its themes identified through literature review and the clinical experience of the research team (see Table 2).

|  |
| --- |
| **General knowledge about CH** |
| * Do you see CH patients in your practice?
* What is the nature of their pain? How do they describe it? What symptoms?
* How does it impact on patients’ lives?
 |
| **Diagnosing CH** |
| * Do you feel confident in making a CH diagnosis?
* What kind of questions do you use in taking a diagnostic history?
* Do you use the current (or are you aware of) ICHD-3 criteria for CH?
 |
| **Relationship between primary and secondary care** |
| * What types of patients are referred to secondary care?
* How is the communication between primary and secondary care?
* What are the challenges and opportunities in your view regarding the relationship between primary and secondary care?
 |
| **Treatment of CH** |
| * What are the medicines for the treatment of CH you are familiar with?
* Are you aware of the use of oxygen and sumatriptan injections in the treatment of CH? Are you confident in prescribing preventive medicine such as verapamil and lithium?
 |
| **Raising awareness of CH** |
| * How can we raise more awareness of CH in Primary Care?
* How can we acknowledge impact of headache disorders, in particular CH?
 |

*Table 2. Interview topic guide*

The interviews were recorded with permission of the participant and fully transcribed. The average length of the interviews was 38 minutes. Data saturation was reached after 16 interviews when no new themes emerged and no further interviews were conducted.29, 30 The study was conducted and reported in accordance with the consolidated criteria for reporting qualitative research (COREQ).31

**Data analysis**

A thematic analysis was performed using NVIVO 12, a qualitative software package.32, 33 The interview transcripts were first read in full by AB and LD to gain an overall perspective of the data. The interview transcripts were then coded thematically line-by-line by AB and LD and a preliminary coding scheme was developed. Other members of the research team (YM and KP) read a number of interview transcript each, added codes and discussed these in detail with AB and LD. The detailed coding framework was refined in a next phase when four overarching themes were identified. In case of disagreement between the researchers, consensus was reached upon discussion with other members of the team.

**RESULTS**

**Sample characteristics**

Sixteen clinicians were interviewed, eight GPs and eight neurologists. Six clinicians were females (five GPs and one neurologist) and 10 males (three GPs and seven neurologists). The mean age of respondents was 49 (GPs = 47, neurologists = 51). Six out of 16 clinicians had a self-declared special interest in headache. The demographic details of the clinicians who participated in the interview study are shown in Table 3.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Clinicians  | Number of clinicians | Gender | Mean age | Special interest in headache |
| Female | Male |
| GPs | 8 | 5 | 3 | 47 | 3 |
| Neurologists | 8 | 1 | 7 | 51 | 3 |

*Table 3. Demographics of the interview participants*

Our data analysis identified four main themes: (1) Challenges with the CH diagnosis; (2) Impact of CH; (3) Challenges with treatment and (4) Appropriateness of referrals to secondary care.

**Challenges with the CH diagnosis**

The misdiagnosis of CH and its consequences is the main theme that runs through the entire dataset. Both GPs and neurologists identified migraine as the most common misdiagnosis of CH. According to clinicians, CH is also misdiagnosed as sinusitis, dental disease, tension-type headache, ophthalmological disorders, trigeminal neuralgia, medication-overuse headache and neck disorders. Our analysis showed multiple factors for misdiagnosis. There is confusion between different terms, for instance between ‘cluster headache’ and *‘cluster migraine’* as one neurologist (N2) put it. Some research participants perceived CH as a series of attacks, as ‘*several attacks of headache close together’* (GP1). Clinicians were aware that many CH patients had unnecessary procedures performed, such as teeth extraction or sinus washouts, before a correct CH diagnosis was made:

‘*I was embarrassed by one woman who is a neighbour who, we were constantly saying she had sinus infection and one of our locums sort of pointed out this is a cluster headache and he was absolutely right.’* (GP3)

Half of the neurologists in our study thought that a lack of awareness of mixed syndromes (e.g., CH and migraine) contributes to misdiagnosis as patients do not present ‘*as the textbooks’* (N8). Neurologists identified that CH patients who have a background pain outside the attacks are often misdiagnosed as migraine. Our analysis showed that, across the data set, unilateral headaches are often perceived as migraine: ‘*unilateral headaches are migraine until proven otherwise’* (N4).

CH was perceived as uncommon and many participants, in particular GPs, were not aware of the associated clinical symptoms. Indeed, GPs participating in the CHIPS study were not confident in diagnosing CH. Neurologists pointed at the lack of robust history taking when patients presented with headache symptoms in primary care:

*‘I am very much interested to know, why does it take too much time to make a diagnosis of cluster headache? And it is such a painful condition and I want to know is it something that the patient doesn't describe? Is it something that the GPs don't listen? Is it something that the GPs don't ask?’* (N1)

**Impact of CH**

*Impact on employment*

There was consensus among all interviewees, GPs and neurologists, that CH has a significant impact on employment:

*‘I've got a few* [patients] *that still work despite the most horrific cluster headache (…) I've got one guy for instance who (…) changed his whole work pattern around his cluster and his family.’* (N3)

Interviewees gave examples of how their patients’ colleagues and employers often do not grasp the severity of the condition: ‘*all these excuses about (…) not being able to sleep, it's just a headache (…) why don't you take a paracetamol’* (N5).Particular emphasis was given by several participants on the night attacks’ impact on attention, concentration and the overall function at work: *‘it makes them feel so unwell that they can't function properly’* (GP2).

*‘This particular gentleman he was almost at the point of losing his job because (…) he was irritable, he was shouting at his colleagues and his boss.’* (N5)

*Psychosocial impact*

According to clinicians, patients with CH are more likely to suffer from psychiatric co-morbidities such as depression, self-harm and suicidality: *‘they may become depressed in the course of illness or even suicidal’* (GP7).The interviewees felt that health professionals should be aware of these co-morbidities and recommend appropriate medical support.

*‘We have probably, have experienced severe pain but this is on a whole different level (…) badly drive people to self-harming, I think that's just an indication of the level of sort of disability.’* (N4)

*‘The psychiatrists feel desperate and helpless because they don't know what to suggest (…) I had two patients sectioned in the last year with cluster headache because of psychosis.’* (N3)

**Challenges with treatment**

*Responsibility of prescribing*

A third main theme identified after analysis revolved around the responsibility of prescribing and the ongoing tensions this caused between primary and secondary care. One GP explained that primary care clinicians, in comparison to their colleagues in secondary care, are more aware of the cost of medication and occasionally override neurologists’ prescribed treatment if the medication is not deemed cost-effective. Some GPs are unsatisfied when the administrative work that comes with prescribing certain treatments is transferred from secondary to primary care. ‘*You act as my clerk’* (GP1), saidone GP referring to the neurologists’ attitude regarding prescribing medications.Although most neurologists explained that they prescribe the medication for CH patients themselves, some admit that there are pressures on cost saving within the hospital.

*‘I* [GP] *suspect there's a kind of pressure from within the hospital as an organisation for people not to do it* [prescribe treatment], *because they don't want the cost coming against the hospital.’* (GP1)

Both GPs and neurologists appreciate that it is more beneficial for the patients when the treatment pathway is determined by the neurologist. This avoids delays in administering the medication.

*‘I usually prescribe all drugs (…) if you try and get the patient to go to their GP, they forget about it, they'll lose their form, the GP is not there, it's just too much hassle (…) if I just write the prescription, it takes me ten seconds to do that and it's much better for the patient.’* (N2)

*Challenges with prescribing oxygen*

For both GPs and neurologists prescribing oxygen was challenging because they were often not aware of prescription practices. Some GPs were not aware that oxygen was recommended as abortive medication for CH. Most GPs who knew about this were often not familiar with the prescription policies. Although in some cases neurologists or GPs were able to arrange oxygen, in other cases they were not aware of the procedure and the responsibility of oxygen prescription was passed on. GPs consider that prescriptions or filling out oxygen forms should be carried out in secondary care.

***‘****I've not been all that successful with oxygen (…) it's very difficult to prescribe, I have in the past but nowadays, I can only think of two patients in the recent past where we've managed…I normally ask the GP to prescribe it but I think they find it pretty challenging to actually get it.’* (N6)

*Challenges with prescribing triptans*

Injectable triptans for CH are expensive and that was one of the tensions between primary and secondary care. Most neurologists felt that although nasal or injectable triptans are recommended due to stronger evidence, GPs occasionally prescribe oral triptans, a cheaper option. Some GPs are willing to prescribe if there is a clear recommendation from the neurologists. One neurologist mentioned challenges with the long-term administration of triptans because of the cost.

*‘They* [GPs] *tend to be happy to prescribe it once they get a letter from us but they don't generally spontaneously prescribe it themselves, I agree with the patients, I think there's a real problem.’* (GP5)

*‘Those illnesses which has got expiry date, so any type of cancer, if the treatment is expensive they know that they only need to give it for a few months, the patient is going to die.’* (N1)

*The use and usefulness of clinical guidelines*

GP interviewees were all clear they would follow the instructions form secondary care when guidelines, like those of the National Institute for Health and Care Excellence (NICE) or those from the British Association for the Study of Headache (BASH), were cited in the referral letter.

*‘I fell out with a few GPs* [about] *lithium and verapamil a few years ago, since the NICE guideline came out in two thousand thirteen, GC150, now I can refer to* [and] *say, look at the NICE guidelines (…) so even though it doesn't have a license NICE is recommending it so you should give it.’* (N1)

Both GPs and neurologists found the NICE guidelines lengthy and ‘*hard to navigate in a busy clinic’* (N12). There was consensus among clinicians that the NICE guidelines are rarely used in practice.

*‘*[The] *website* [NICE website] *comes up with a lot of extraneous material when you try and search on specific things, you have to go through quite long lists sometimes to find a specific tag on what you're looking at, then the guideline is often quite lengthy and I think NICE are probably losing their way.’* (GP3)

**Appropriateness of referrals to secondary care**

*Referrals*

GPs mentioned that they rarely refer headache patients to neurology departments in secondary care. In other cases, even if GPs felt confident in making a diagnosis, referrals were made as certain treatments are usually initiated in secondary care (e.g., verapamil, lithium). Other reasons for referrals by GPs to secondary care services included to offer patients reassurance and because of patients’ anxiety and pressures to see a specialist, despite GPs’ confidence in managing the headache condition. Some GPs expressed frustration that they need to *‘know everything about everything’* (GP4)and are expected refer less patients to secondary care. One GP mentioned that patients get referred ‘*to be managed not to be advised on’ (GP7).*

*‘Patients will not be satisfied if they just go there* [neurology services] *once and say, well he* [the neurologist] *sent me with this list of recommendations, and it's down to us* [GPs] *to try it and if it fails, and it normally fails, what do you do next? Do you refer them back saying, I've tried all the options and nothing works? I think they* [neurologists] *need to be more proactive in following these patients up after the recommendations are made.*’ (GP7)

Some neurologists complained of poor history taken by GPs, reflected in short clinic letters. Others deemed the referrals inappropriate when only minimal analgesic treatment was tried. Most neurologists felt that referrals have increased in recent years but also acknowledged that this could be the result of increased demand and lack of resources. Treatment resistant headaches, CH and medication-overuse headache were considered appropriate referrals to neurological services by one neurologist.

*‘Most of the cluster headache that I'm making a diagnosis are very simple cases, first letter from GP saying this patient has daily headaches for the last few months, please advise, and when I take the history, they have cluster headache and then I find out that they have had these headaches for fifteen odd years.’* (N1)

*Brain imaging*

Neurologists acknowledged that GPs are pressured by patients to refer to secondary care or to arrange brain imaging. Many research participants expressed that if patients would be required to pay a fee for the consultations they ‘*would abuse the system much less’* (N2). One neurologist mentioned that occasionally patients have to be rescanned as patients wish to be reassured: ‘*only lasts about a year as far as reassurance goes’*(GP2). Some clinicians felt that the incidental findings are causing additional anxiety to patients and unnecessary referrals and waste of resources.

*‘They* [patients] *often say to the GP I don't want to see you, you're not a specialist, I want to go and see a neurologist and I want to have MRI scan.’* (N2)

*‘I think one of the problems is that probably too many people are getting scans for headaches (…) incidentalomas are being sort of picked up (…) wasting a lot of money and causes a lot of anxiety when all you wanted to really do is to reassure that person.’* (GP3)

**DISCUSSION**

**Summary**

GPs and neurologists recognise that CH is often misdiagnosed as migraine, sinusitis, trigeminal neuralgia, tension type headache, dental or ophthalmological disorders. Frequent attenders in primary and secondary care services, patients with CH have unnecessary procedures performed such as sinus washout or teeth extraction, which is in line with previous data.35 Confusion between the terms ‘cluster headache’ and ‘cluster migraine’, short consultation time for GPs, lack of awareness of mixed syndromes, poor history taken by clinicians, poor description of pain by the patients contribute to delays in diagnosis and misdiagnosis. CH has a significant impact on patients’ employment and mental health, increasing the risk of depression and suicide. GPs are unsatisfied when the administrative work of prescribing or filling out oxygen forms is transferred from secondary to primary care. Neurologists admit that pressures within hospitals regarding prescribing contribute to tensions between primary and secondary care. GPs occasionally override the specialist advice and prescribe cheaper drugs (e.g., oral triptans instead of injectable or nasal triptans). Patients’ anxiety, their need for reassurance and their insistence to see a specialist are other reasons for referrals to secondary care, despite the GPs’ confidence in managing the headache condition.

**Strengths and limitations**

This is the first qualitative study on CH with a robust sample of GPs and neurologists. The diversity of research participants aimed to capture the range of views on the understanding and experiences of CH from both sides of the care. This is the first study of its kind to explore both GPs and neurologists’ perceptions and the interface between primary and secondary care with regards to CH. The multidisciplinary research team, led by an experienced medical sociologist (LD), comprised of a number of experienced headache specialists (AB, KP, PJG, FA). A limitation, characteristic for all qualitative studies, was that clinicians were informed in advance that they were taking part in a study on CH. It might be the case that they looked up some information about CH prior to the interview. Although this was not reflected in our findings as many clinicians were upfront and honest about their knowledge around CH. We recognise the gender imbalance of the neurologist participants (7 male and 1 female) although this reflects the reality of the gender gap in neurology.36 Gender and CH is an important angle of study with seminal work by sociologist Kempner, for instance how gender appears to overdetermine understandings of CH.37 We identified gender as an important theme in our analysis of the patient dataset in our CHIPS study, but that is beyond the scope of this paper which focusses on healthcare professionals.

**Comparison with existing literature**

Although CH is the most severe primary headache,3 there are only a few qualitative studies on CH available. These include the patients’ experiences living with CH,24 the use of alternative pharmacological treatments25 and gender dimensions of CH.37 CH is regarded as a male dominated disorder, although there is increasing evidence that many women suffer with CH.37 This is reflected by the decreasing male:female ratio from 5-6:138, 39 or 8-9:140, 41 by other studies to an estimated 2-3:1.42-44

Despite headache being the most common cause of neurological referrals,45 diagnosing primary headache remains challenging for GPs.46 There are conflicting views of the importance of the exact diagnosis in patients with headache47 as many patients have a self-limiting headache of benign origin.48 The strategy of therapeutic trial or ‘watch and wait’ usually applied in primary practice48 is detrimental to less common conditions such as CH. When consulted by patients with headaches, GPs considered it less relevant to make a specific diagnosis and the course of time was used as main diagnostic tool.47

GPs often act as gatekeepers49 and triage between patients who will be treated in primary care50 and those who need specialist input from neurologists or need a referral to specialised headache units. That gatekeeping role has many positive effects: lower health service use, decreased expenditure and better quality of care.49 One important challenge is that such gatekeeping may delay a timely diagnosis and, as a consequence, delay treatment for patients suffering from uncommon conditions which present with common symptoms, such as CH.51 This, in turn, could result in referral delay, reduced quality of life and unnecessary healthcare costs.51 Significant diagnostic delays in CH and consulting multiple health professionals cause a substantial and avoidable burden on the health system.52 Other conditions such as cancer face delays in the diagnosis53, 54 as a limitation of the gatekeeping system when uncommon conditions present with common symptoms.51 Although the frequency of diagnostic errors was found to be low in the primary care in UK, the human cost was relatively high for half of those experiencing an error.55 Current measures of quality of care in primary care are not focused on diagnostic delays and errors.56 Misdiagnosis can be prevented by access to GPs with special interest (GPwSI), which decreases the waiting time, referrals and cost.57

The clinical usefulness of treating headache from a biopsychosocial rather than a narrow biomedical perspective has been documented.62-65 The use of such biopsychosocial approach, and implementation of psychological interventions, are increasing in the headache field.59-61 Although the comorbid psychopathology6 and impact on social life for CH are well documented7, the biopsychosocial model has not yet been widely implemented in CH. It is high time that also CH is managed via a biopsychosocial approach in both primary and secondary care settings.58

**Implications for clinical practice and research**

A first step for GPs is to be aware of CH and to understand that it is very different from the more common headache disorders, such as migraine and tension-type headache, in terms of treatment and pathophysiology. GPs that are not experienced or aware of CH, should be able to recognise when dealing with a distinct syndrome and further refer to secondary care.12 Most clinicians in this study are supportive of programmes of raising awareness among GPs. There are concerns that raising awareness among patients could have possible negative effects on GPs’ workload and patients themselves. More training programmes for GPwSI could improve the patients’ outcome by preventing delays in diagnosis and misuse of resources. It was previously emphasised that training should not only target the individual, but also focus on organisation issues.66 Clear prescribing responsibilities could avoid the tensions and improve the interface between primary and secondary care. NHS commissioning policies are causing a divide between primary and secondary care and competition for resources. Our study shows that hospital doctors shift the prescribing cost from secondary to primary care. This practice has a negative impact on patients. Workshops for primary and secondary care doctors could raise awareness of the challenges on both sides of the care. Coherent management pathways for headache could improve the referrals and healthcare cost.

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**Ethical approval:**

The study gained ethical approval from the University of Hull (Ref. 20142015005) and from the National Research Ethics Service (Ref. 15/NW/0039).

**Author contributions:**

**AB:** Facilitated recruitment of patient participants,substantially contributed to data analysis and manuscript drafting. **FA:** Co-designed the study with LD, facilitated recruitment of patient participants, promoted study in the headache community, contributed to research team meetings. **YM:** Conducted an analysis of the data in NVivo and discussed with LD as a medical student on an ASPIRE summer project at Keele’s School of Medicine. **KP:** Providedinput in protocol writing, contributed in research team meetings, analysed and discussed interview transcripts. **PG:** Provided input in protocol writing, contributed in research team meetings.**LD:** co-designed the study with FA, wrote the funding application and led the organisation of the CHIPS study, developed study protocol, prepared project documents and ethics application, conducted all CHIPS interviews and prepared the draft manuscript with AB. All authors have read the draft critically, have made contributions and have approved the final text.

**Competing interests:**

FA served as an advisory board member for Allergan, Novartis, TEVA, Electrocore and Eneura and received an honorarium which he donated to the charitable organisations (Migraine Trust, BASH and ADMA). KP has received honoraria as a speaker and/or consultant, and/or received research support, from Allergan, Amgen/Novartis, Autonomic Technologies Inc., Ely-Lilly and Teva. PJG reports personal fees from Allergan, and related grants and personal fees from Amgen and Eli-Lilly and Company, and personal fees from Alder Biopharmaceuticals, Autonomic Technologies Inc., ElectroCore LLC, eNeura, Impel Neuropharma, Mundipharma, Novartis, Teva Pharmaceuticals, Trigemina Inc., and WL Gore; and personal fees from MedicoLegal work, Massachusetts Medical Society, Up-to-Date, Oxford University Press, and Wolters Kluwer; and a patent Magnetic stimulation for headache assigned to eNeura without fee. AB, LD and YM have no competing interests.

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