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## Headache: The Patient's View

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### Abstract

**Introduction:-** Headache is the commonest reason for neurology referrals, and the commonest neurological reason for patients attending Emergency Departments (EDs). An ethical approach to health care requires that patients be provided with informed choice about management. However researchers have not addressed patients' concerns and choices in managing headache. This study aims to describe the views of patients, their fears, use of EDs, their perceived need for a scan and its outcome for them.

**Methods:-** A qualitative study using semi-structured interviews with 19 adults aged 23-63, referred by Family Practitioners (FPs) to neurologists for primary headaches approximately two years previously. Audio-recorded interviews were transcribed and analysed thematically.

**Results:-** Participants described fears about secondary organic causes for headache, like a brain tumor. They described their headaches as stressful, and leading to a vicious cycle of fear. Many believed they needed a brain scan and requested it. Participants reported relief of their fears after a scan, and in some cases relief of headache symptoms.

**Discussion:-** UK FPs now have open access to brain scanning, which may relieve physical concerns. Interventions to address health-related anxiety may also help some consulters for headache.

**Keywords:** Headache; Referral; Diagnostic Imaging; Anxiety; Emergency Medical Services

### Introduction

In the diagnosis and management of patients, doctors are asked to respect four principles, to:- provide patients with informed choice (autonomy), cause no harm (non-maleficence), do good (beneficence), and promote justice, which includes fair, cost-effective allocation of scarce resources [1]. The last principle is salient in most western countries where health care is funded as a public service. Guidelines for physicians tend to focus on management with medicines [2]. How to apply the principles to decisions like investigation and referral to specialists is under-investigated and challenging, particularly for doctors presented with headache.

It has been argued that scanning patients for headache, whether it is by computer tomography (CT) or magnetic resonance imaging (MRI) may do more harm than good [3]. Incidental findings are common, particularly with MRI, occurring in 2% of scans of people with no neurological symptoms [4]. When patients consult a primary care physician for an undifferentiated headache, the 1-year risk of a malignant brain tumor is 0.15%, rising to 0.28% above the age of 50 years [5]. Scanning for headache alone has a low predictive yield. On the other hand, referral to a neurologist for an expert assessment and access to scanning is more expensive [6]. Headache is one of the commonest symptoms reported, and 4% of adults consult their primary care physician for it each year [7].

Even though Family Practitioners (FPs) refer only 2% to neurologists, it accounts for 25% of new neurology referrals [8]. This limits access to neurologists for people with other important conditions like epilepsy and Parkinson's disease. This has led to the argument that FPs should have direct access to scanning, reducing unnecessary referrals to specialists [9,10].

Because of concerns about poor use of resources, we undertook a prospective study of a cohort of people consulting FPs for headache, and compared them to a cohort referred to neurologists [11]. We found no differences on any measures of headache severity, impact or disability between patients managed by FPs and those they referred to neurologists. However, patients who were referred were more anxious about their headache symptoms and consulted more frequently [11]. Using qualitative methods, we found FPs felt pressured by patients to refer, particularly for scanning, to rule out a brain tumor [12].

This and other research has focussed on the perspectives of doctors as decision-makers, and ignored the patients' view. The aim of the current study was therefore to describe the views of patients diagnosed with headache who have been referred by their FP to a neurologist for headache. We conducted semi-structured interviews with patients with the aim of eliciting their personal worries and beliefs regarding their headache and how this influenced their actions. Particular attention was given to their perceived need for a scan and its effect.

## Methods

**Design:** This qualitative study, which was nested in a prospective cohort study, sought to provide a detailed knowledge of the views and experiences of patients with headache who had been referred by their FP to a neurologist. Qualitative methods were ideally suited for such hitherto unexplored research topics as participants are able to raise what they personally regard as important aspects and concerns rather than these being specified in advance by the researcher. The South-East Multi-Centre Research Ethics Committee approved the study (MREC01/01/032). Informed consent was obtained from all participants.

**Recruitment:** Participants were recruited from a cohort of 48 adults (aged > 18 yrs) with headache who were prospectively recruited after they had been referred by their FP in the south of England to a neurologist for headache [11]. This mean age of participants in this sample was 41 and 64% were female. We slightly over-sampled men given their smaller numbers in the cohort and selected individuals with a similar age distribution as the cohort. These patients were approached by letter to participate in this interview study with a response slip. A follow-up phone call was made to non-responders.

**Data collection:** Semi-structured interviews undertaken by a researcher independent of the cohort study (LJ), lasted on average 45 minutes, and were conducted in a location of the participant's choice. A topic guide was used to frame the interviews. This was developed on the basis of themes identified from the literature and refined through open interviews.

The main themes covered were patients' experience of having a headache disorder and its impact on their lives, including their fears and concerns; their use of hospital Emergency Departments, whether they had been referred for a scan, how this had occurred and how helpful this had been. Interviews were conducted on average two years after referral to a neurologist to provide a long term perspective. Participants were encouraged to talk freely and the interviewer probed and prompted responses as required. Information of the participants' headache diagnosis was from the database of information collected for the cohort study in which these people had previously participated [11].

**Data analysis:** Interviews were audio-recorded and transcribed verbatim. Data were entered into NVivo 9 a computerized qualitative analysis package. FN read each transcript line-by-line and generated codes through open coding. These codes were then categorized thematically and relationships between themes were identified through a process of constant comparison, with particular reference to explanations for patients' decision making and the beliefs and experiences of 'deviant cases'. LR, AN and MM reviewed the codes and categories and discussed emerging interpretations.

## Results

### Sample Characteristics

A total of 19 people comprising 8 men and 11 women were interviewed (Table 1). Thirteen had been categorized as having migraine, three chronic daily headaches and three as 'other headache'.

Analysis of the transcripts provided insights into patients' fears about the cause of their headache and the implications that this had for their use of different health care services. Three key themes were identified. These were: headache-related fears and use of emergency departments; perceived need for a scan; and the outcome of a scan in terms of perceived reassurance. Quotations are presented to illustrate themes.

### Headache-related fears and use of Emergency Departments

Patients generally identified fear about what their headache might mean as a key issue prompting service use. One patient mentioned her worry and anxiety reaching up to a point: 'It's a, what's called a *tipping point* really I think, you know if you think of catastrophe theory that something will grow up to that point and suddenly it will tip.' (P.12, Female, 47).

For 3/19 participants, severe headaches made them resort to Emergency Department (ED) visits to a hospital after they had seen the FP. One said: 'the one that was really frightening I ended up in X Hospital because it developed into what I thought that I might have been having a heart attack, because I was so worried about the headache'. (P.5, Male, 50).

Continuous headache also led relatives to act on the patient's behalf. One said: 'it was like a continuous thing every weekend...my parents would take me up the hospital, thinking there was something wrong, and what it was, was migraine.' (P.6, Male, 23).

### Perceived need for a scan

Worry about a serious medical problem led ten participants to ask their doctor for a brain scan. Altogether eight of these patients received a scan subsequently. Before the scan, these patients described consistent fear of a possible physical cause, mainly a brain tumor. Patients described their headache as not reducing after advice given by their FP, and believed they needed to persist to get their doctor to arrange scan.

'...I wanted to be treated. I wanted somebody to tell me that I wasn't gonna have a brain tumor and fall down dead.' '...But I actually found I had to push for a scan, I had to insist on it almost, and yet that was the thing that had been the most worrying right from the very beginning... I had to insist on something, something physical being done.' (P13, Female, 38).

These patients generally explained that they had been referred for a scan for peace of mind: 'Yes because I got so worried because it had gone on for so long and they said we'll send you for one for peace of mind, we're saying we know there's no problem up there, but for peace of mind for you we'll send you for one.' (P.7, Female, 54)

An additional three participants who had been referred and seen a neurologist reported having brain scans that were initiated at the request of a neurologist, rather than themselves

### The outcome of a scan in terms of perceived reassurance

Following the scan, 6/8 of the participants who reported asking for a scan, stated that their anxiety, stress, and worry had reduced considerably, and described themselves as 'relaxing a bit'. Three of these patients reported that normal results from the scan reduced their headache symptoms also: 'But I think I had the scan to put my mind at rest. I knew that there was nothing serious about it. But perhaps even that may have made the fact that it's tailed off, you know, sort of eased it on its way sort of thing.' (P19, Female, 63).

After the scan one participant reported the headaches diminished to such an extent they were no longer consulting their doctor.

**Table 1:** Participant characteristics

Participant ID	Age	Gender	Ethnicity	Marital status	Employment status	Headache type
1	43	Female	White	Single	Unemployed	CDH
2	39	Female	Black	Single	Unemployed	Undefined
3	33	Male	White	Single	Employed part-time	CDH
4	47	Male	White	Married/living with partner	Employed full time	Migraine
5	50	Male	White	Married/living with partner	Employed full time	Migraine
6	23	Male	White	Single	Employed full time	Migraine
7	54	Female	White	Married/living with partner	Employed part time	Migraine
8	28	Male	White	Married/living with partner	Employed full time	Migraine
9	60	Male	White	Married/living with partner	Unknown	Migraine
10	49	Female	White	Married/living with partner	Employed full time	CDH
11	50	Male	White	Single	Employed-part time	Cluster
12	47	Female	Mixed race	Married/living with partner	Unknown	Migraine
13	38	Female	White	Married/living with partner	Employed full time	Migraine (aura)
14	45	Female	White	Married/living with partner	Employed full time	Migraine
15	53	Female	White	Married/living with partner	Self-employed	Migraine
16	43	Female	Black	Single	Employed full time	Migraine
17	38	Male	Black	Married/living with partner	Employed full time	Undefined
18	54	Female	White	Married/living with partner	Employed full time	Migraine
19	63	Female	White	Married/living with partner	Employed-part time	Migraine

**Notes:** The headache diagnosis listed is that made by the neurologist. Chronic daily headache is abbreviated to CDH.

## Discussion

### Summary of main findings

We found most people with headache who were referred for a scan described fears about a physical cause for their headaches, in particular a brain tumor. Patients believed they had needed to put pressure on their doctors to get a referral for a scan. They typically described feeling relieved after a normal scan, with one reporting alleviation of headache symptoms altogether. After a scan most felt they had the confidence to use other strategies to manage their headache.

## Strengths and limitations of this study

This qualitative study consisted of interviews with men and women recruited from a large cohort of patients who had been referred for headaches about two years earlier [11]. It is one of few qualitative studies to explore patients' ideas and experiences about headache [13]. It is the only one we know to explore patients' views about their role in decision-making about referral and investigation by a neurologist. It was not large, and no participants reported scans leading to incidental findings which might potentially increase their anxiety.

## Relationship to other studies

We previously interviewed FPs to determine their views of reasons for referral, and found they felt patients pressured for a scan mostly because of fears of an organic cause [12]. Some of our participants described a cycle of worry which included visits to the ED. Headache is a common neurological reason for ED visits, which is something health services planners are seeking to reduce owing to their high cost. After scanning our participants reported their fears were reduced, and sometimes their headache symptoms too. These findings add depth to evidence from a trial which found that scans do not on average increase patients' fears [14]. In this trial the fears of those scanned were reduced after 3 months [14]. Health services for patients who were randomized to no scan cost more, as those denied scans were more likely to have visited another neurologist, with up to a third being given a scan later [14].

It has been suggested that up to a third of patients referred to neurologists, particularly those with headache have symptoms unexplained by organic disease [15], with an implication that addressing health anxiety is important also. Some of the participants in this study described health anxiety, and some resorted to visiting the hospital on an emergency basis. There is evidence that, in addition to conventional therapy, relaxation, behavioural and cognitive-behavioural management may help people with headache and migraine, particularly when it is associated with anxiety [2,16,17].

## Implications for clinical practice and research

If doctors wish to respect patient autonomy, our evidence suggests some patients choose a scan. Communication about the likelihood of negative results, false positives results and cost, would also contribute to informed consent. Our participants were interviewed an average of two years after referral to a neurologist. They reported a negative result had helped relieve their fears, and move on to self-management. Open access to brain scanning for doctors working in primary care may reduce anxiety, reduce cost and increase access to neurologists for other patients. More research is required to determine whether patients with health-anxiety, who are additionally offered relaxation and cognitive-behavioural can reduce headache and improve quality of life. We are currently exploring this by means of a trial (NIHR PB-PG-0610-22373).

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