

Paul T.G. Davies
Chris J. Glynn
Miriam A. Kadry

Expectations of patients attending a combined headache clinic

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P.T.G. Davies (✉)
Department of Neurology,
Radcliffe Infirmary,
Oxford, UK
Tel.: +44-1604-545850
Fax: +44-1604-544540

C.J. Glynn
The Pain Relief Unit,
Churchill Hospital,
Oxford, UK

M.A. Kadry
Department of Anaesthesia,
West Middlesex Hospital,
Twickenham, London, UK

Abstract We audited the expectations of patients referred to a combined headache clinic from a specialist headache clinic and a pain relief unit due to the intractable nature of their headache. Our aim was to assess the expectations of definitive diagnosis for the cause of headache, as well as the acceptance of its symptomatic management. We reviewed the notes of all patients referred to the combined clinic over a 2-year period from January 1998 to January 2000. It has been standard practice in the clinic to document patients' expectations of definitive diagnosis for the cause of their headache and for its symptomatic treatment. Fifty-two patients (29 women, 23 men; mean age, 40.5 years; range, 15–76 years) were referred to the combined clinic over the two years. These patients had been selected from a total of 460 new patients seen in the specialist headache clinic over this period. All patients had been reviewed by at least one consultant neurologist. Nearly all suffered chronic daily headache of mean duration 8.25 years (range, 1–40 years). Only three patients suffered from migraine as well. Forty patients

(77%) were still concerned about the cause of their headaches; 13 (33%) of these wanted further investigations. Fourteen (27%) of the original 52 patients were discharged from the clinic, 9 (17%) were satisfied and accepted symptomatic management of their headache, 5 patients (10%) were unsatisfied and were still looking for a cause for their pain. Five more patients (10%) who demanded further investigations failed to keep follow-up appointments. The remaining 33 patients (64%) accepted symptomatic management within the clinic. One in five patients (20%) attending a tertiary referral clinic for symptomatic treatment of chronic headache did not want symptomatic treatment. They wanted to know the cause of the headache and be provided with a cure. This observation is important when one is assessing outcome measures, because 20% of these patients did not want symptomatic management, the only treatment on offer.

Key words Chronic daily headache • Intractable headache • Headache clinic • Patients' expectations

Introduction

Headaches are among the most common complaints to healthcare professionals. Patients with headache consume vast medical resources as they get referred to different

specialists in an attempt to achieve a diagnosis and to control their pain. Failure to find an underlying cause for headache or give an accurate and informative diagnostic label sometimes makes the management of these patients difficult. They may then be referred to a specialist headache clinic.

In the UK there are relatively few specialist headache clinics. They are usually run by neurologists, relatively few of whom will have had specialist training in pain management. Most patients who attend such clinics will be given a diagnosis according to the International Headache Society (IHS) Classification of Headache [1] but some patients, particularly those who have suffered constant or near-constant headache for years, may have headaches that are difficult both to diagnose and to treat. It is a generally held view that the IHS classification of chronic headache needs improving, but we must remember that it is a classification of headache types and not headache patients. Chronic head pain can be defined as an unpleasant sensory and emotional experience that the patient considers may represent on-going or potential cranial tissue damage. It follows that not only the headache type but also the emotional state of these patients and *their concepts and perceptions* of the significance of their pain problem need to be addressed. Indeed these factors may be more important in headache management than the diagnostic label.

In an attempt to address the needs of patients who failed to get satisfaction from the specialist headache clinic in Oxford (run by P.T.G Davies), we set up a combined clinic in 1995 where a consultant neurologist from the specialist headache clinic and a consultant anaesthetist from the pain relief unit saw these patients together. The treatment of the vast majority of headaches is symptomatic, whether patients are seen in primary care, accident and emergency departments, neurology clinics or specialist headache clinics. There are occasional headaches for which there is a definitive cause and that require definitive treatment. However, the vast bulk of headaches require symptomatic management. This symptomatic management almost always revolves around drugs. These drugs can be used reactively, i.e. the headache can be treated when it comes, for example with the triptans in the case of migraine. The other possibility is to proactively use drugs such as antidepressants and anti-convulsants to prevent the headaches coming. Psychological interventions can sometimes help headaches and can be used either proactively or reactively, but for the vast majority of headaches there are no injections or operations that will make a significant difference.

It is the practice within the pain relief unit to ask early on the patients' expectations of the consultation and the pain relief unit, and specifically to ask them if they would accept symptomatic management of the pain. This is the only treatment that we have available for patients referred to the pain relief unit and it is important that the patients understand this. This question was asked as part of the assessment of all patients attending the combined headache clinic. Although we initially decided to concentrate on the symptomatic treatment of these patients, it became clear that this was not what the patients expected. Some patients' perceptions and expect-

tations of their headache and its treatment were not always similar to ours! This incongruity, an understanding of which is of fundamental importance to headache patient treatment, has not been widely studied. Packard [2] noted it and found that patients attending a headache clinic were much more likely to be interested in finding the cause of their headache and much less interested in its symptomatic treatment than the doctors had thought. Since then there has been very little published work in this important area. We decided to audit our patients to determine what their expectations were of the medical profession.

Patients and methods

The medical notes of 52 consecutive patients attending the combined headache clinic from January 1998 to January 2000 were studied. Nearly all patients suffered daily or near-constant headache, so-called chronic daily headache. All patients were seen individually and assessed in either the specialist headache clinic or in the pain relief unit before they attended the combined headache clinic with both the consultant neurologist and the consultant anaesthetist.

The neurologist who had previously seen these patients in the specialist headache clinic believed he had reassured the patients about the benign nature of the headache and had tried unsuccessfully to provide symptomatic management.

In the combined headache clinic, patients were seen by a panel of doctors which included the consultant in the pain relief clinic (CJG), consultant neurologist (PTGD), a specialist registrar in anaesthetics and the visiting doctor on clinical attachment. A structured questionnaire was used prior to the consultation to cover pain parameters and patients' psychological characteristics.

All patients were asked about what they thought their headaches were due to, whether they felt they had been sufficiently investigated and what were their expectations of the consultation. They were reassured that there was no serious underlying cause. They were asked whether they were expecting further investigations leading to a cure or symptomatic management. All previous consultations, investigations and failed therapies were documented. Excessive use of analgesics was noted and treated as appropriate. Symptomatic treatment and referral to the clinic's psychologist were offered on a case-by-case basis according to our clinical judgement.

Results

Fifty-two patients (29 women and 23 men) were referred to the combined headache clinic during 1998 and 1999. Fifty came from the specialist headache clinic and 2 from the pain relief unit. During this period, 420 new headache patients were seen in the specialist headache clinic (i.e. about 12% of

Table 1 Patients with a neurological or surgical condition prior to the onset of headache and whether or not they were concerned about the cause of their headache

Patient	Disorder	Referred by	Concerned about the cause of headache?
1	Acoustic neuroma	Neurosurgery	No
2	Midbrain stroke	Neurology	Yes
3	Head injury	Neurology	Yes
4	Head injury and carotid dissection	Neurology	Yes
5	Sarcoid	Neurology	No
6	Carotid endarterectomy	Vascular surgery	Yes
7	Head injury and concussion	Neurology	Yes
8	Skull fracture and extradural haemorrhage	Neurology	No
9	Pituitary tumour	Endocrinology	No
10	Occipital AVM with multiple embolisations	Neurology	Yes
11	Cholesteatoma	Skull base clinic	No
12	Head injury	Neurology	No
13	Cerebral infarct	Neurology	No
14	Calcium deposition on brain CT	Neurology	Yes

AVM, arteriovenous malformations; CT, computed tomography

patients were referred). The median age of these patients was 40.5 years (IQR, 33.5–54.0 years; range 15–76 years). They had suffered from headache for a mean of 8.25 years (range, 1–40 years). All had previously seen at least one consultant neurologist regarding their chronic headaches, one patient had seen three. Nearly all could be labelled as suffering from chronic daily headache. In 14 there had been some neurological or surgical event or operation prior to the onset of headache but none had a progressive disorder and all had been discharged from neurological or surgical follow-up. Their conditions, and whether they were concerned or not about the cause of their headache, are shown in Table 1. Many had had headache for so long they couldn't remember how it started. Twenty-six patients (50%) had been investigated with computed tomography (CT) or magnetic resonance imaging (MRI) of the head, seven of whom wanted further investigations.

Forty patients (77%) were still concerned about the cause of their headaches, 13 (33%) wanted further investigations but most were unclear as to what those investigations should be. Thirty-five patients (67%) were more concerned about finding the cause for their headache than receiving symptomatic treatment. By addressing their unrealistic expectations and erroneous beliefs, we were able to reassure 25 patients (71%). Fourteen (27%) of the original 52 patients were discharged from the clinic, 9 (17%) were satisfied and accepted symptomatic management of their headache, 5 patients (10%) were unsatisfied and were still looking for a cause for their pain. Five more patients (10%) who demanded further investigations failed to keep follow-up appointments. The remaining 33 patients (64%) accepted symptomatic management within the clinic.

Discussion

About 40% of the patients seen in specialist headache clinics in Britain suffer from migraine and about 40% from chronic daily headache. While there are a number of causes for chronic daily headache, e.g. analgesic misuse, chronic neck problems and chronic tension-type headache, there remains a significant group of chronic headache sufferers whose headache is difficult to classify according to the IHS criteria. This can make the clinical management of these patients more difficult as there is no clearly defined treatment pathway. It comes down to best clinical judgement, although best judgement may not be acceptable to the patient if what is offered significantly differs from what the patient wants from the consultation.

It was surprising to find that 77% of patients who were referred from a symptomatic management headache clinic to the Combined Headache Clinic were still concerned about the diagnosis. It could be argued that the reason why these patients were not responding to previous symptomatic management provided for their headaches was because of these expectations. Why had these concerns not been fully appreciated by the medical profession? We can speculate that patients expect doctors to find the reason for their headache and if they do not then insufficient investigations have been performed or perhaps the doctor is just not good enough. While some patients may theorise as to the cause of their headaches, the medical profession is sometimes unable to completely discount a rather unlikely hypothesis. Sometimes we have to say we do not have the answer.

Labels like chronic daily headache, chronic tension-type headache or new persistent daily headache often do little to

enlighten the patient (or doctor) and we feel they are of little help in the management of the highly selected patients we saw in this clinic. In migraine, which is a condition better defined, understood and, arguably, treated compared with chronic daily headache, uncertainties and myths still abound but at least patients understand, more or less, what is wrong.

Patients dwell on the diagnosis because they often think the medical profession must make a diagnosis before being able to effectively treat headache. Indeed they may refuse symptomatic treatment because it masks the underlying pain, the severity of which they may perceive as a way of monitoring their underlying disorder. We know from the history and results of imaging that the chronic pain is not an indication of anything medically sinister or serious, nor an indication of ongoing damage, but for the unreassured patient it may not be seen in those terms.

By addressing these unrealistic expectations as well as erroneous beliefs, it was possible to reassure 25 (48%) of these patients; we were unable to reassure 10 (20%). These 10 either failed to attend for follow-up or informed us that they did not want symptomatic management. It would be interesting to know if these patients were consulting other specialists for investigation or treatment. Thus a major failure of treatment (20%) in this combined clinic was with patient dissatisfaction with the service offered, because of their unrealistic expectations and erroneous beliefs.

It is difficult to know how to overcome these two problems, as both consultants were aware of them in the 5 patients (10%) who returned to the clinic seeking reassurance yet neither consultant could reassure these 5 patients. If this figure of 20% can be extrapolated to all headache and pain clinics, it would mean that 1 in 5 patients will fail to be satisfied because they do not want symptomatic treatment for whatever reason. This has enormous connotations when one comes to address outcome measures.

We accept that with our ill-defined patient population it is difficult to say how our findings could be extrapolated to more general headache populations. Nevertheless we believe that a number of important principles have emerged which are not well recognised by neurologists and there is little published work in this area. Our study emphasises, in this group of patients (mean duration of headache, 8.25

years) at least, that a major reason why headache can be intractable is a perceptual one. If the patient cannot be reassured of the benign nature of the condition, if no medical explanation which is demanded by the sufferer for their headache is acceptable, or if symptomatic treatment is refused, then the doctor is unlikely to help the patient. Patients' expectations have to be realistic but sometimes it can be difficult to determine exactly what the patient wants.

Wadsworth and Ingham [3] noted how difficult it is to define illness precisely, and this seems particularly true for chronic headache that has neurochemical, pathophysiological and psychosocial determinants. Each of these has, to varying extent, been investigated in headache but some reference is needed to how sufferers see the disorder reflecting or influencing the lives they are leading. Patients' perceptions must be considered.

Prior to 1983, only one paper [2] had focussed on the differences in perception between headache patients and their physicians. Packard compared the wants of 100 patients with differing headache diagnoses with what a group of doctors thought they would want. He found that patients rated a need for diagnosis and explanation much higher than symptomatic treatment, contrary to what doctors had rated. Barnat and Lake [4] further explored patients' perceptions of their headache disorders using a survey form and emphasised that "comprehensive treatment should address the emotional dimensions of pain and the manner in which headache patients attempt to deal psychologically with this disorder." There have been no further published studies to our knowledge comparing patients' and doctors' perceptions in headache management. Dawson et al. [5] emphasised the importance of the doctor-patient relationship in shaping patients' expectations in pain management and we, too, recommend that future research on outcome measures in pain management, the instigator of this audit, place greater emphasis on the potential impact of the patient-provider relationship.

More work is therefore needed to investigate the paradox of why many patients continue to seek medical help for their chronic headache, perhaps over many years, yet are often unconvinced by medical reassurance, explanations and suggestions for symptomatic treatment.

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