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The patients' perceptions of migraine and chronic daily headache: a qualitative study

Received: 9 March 2004
Accepted in revised form: 19 October 2004
Published online: 25 January 2005

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Abstract This study aimed to gain insight into the management of migraine and chronic daily headache (CDH) from the patients' perspective. This article outlines the patients' perceptions of migraine and chronic daily headache. Thirteen semi-structured interviews were carried out with patients suffering from IHS migraine. Five patients, due to their headache frequency of more than 15 headache days per month, were classed as CDH patients. The data were transcribed verbatim and analysed in accordance with the grounded theory methodology. The main themes were: headaches, impact and headaches related to health issues. The theme

'headaches' was sub-divided into 'their pain and symptoms', 'differentiating between their headaches' and 'perceptions of headaches as barriers and facilitators to management'. The patients' perceptions of migraine and CDH were sometimes conflicting and influenced the patients' management behaviours. The qualitative methodology may help to inform doctors, other healthcare professionals and headache researchers about the patients' perspective and possibly develop future headache research, care and education.

Key words Migraine • Chronic daily headache • Patient • Perceptions

Introduction

High-impact headaches such as migraine and chronic daily headache (CDH) affect 12% [1] and 3.2–5% [2, 3], respectively, of the general population. These headaches can cause disability and impair quality of life. Over 70% of migraine patients reported at least some disability, with about 30% of the migraineurs reporting severe disability [4]. Quality of life is significantly reduced in migraineurs when compared to healthy controls [5]. CDH has an even greater impact than migraine [6], with quality of life being

more severely reduced in patients with CDH than in patients with episodic migraine [7].

Few studies have been published on the patients' perceptions of migraine and even fewer data are available on the patients' perceptions of CDH. Gaining better understanding of the patients' beliefs and attitudes is important as these may have an influence on the patients' management behaviour. Of migraine patients who had never consulted, 17% believed that their doctor would not treat their migraine seriously enough, 76% said that they did not need a doctor's opinion to treat their migraines, 52% reported that their headaches were

not that bad and 50% said that they had a treatment option that worked [8]. However, 42% of those with headaches in the US said that there was nothing the doctor could do, 41% said that seeing a doctor was too inconvenient and 32% said that seeing a doctor was too expensive [9]. However, the outcomes might be different in the UK, where seeing a doctor is free at the point of contact. The lapsed consulters (65%) reported that they had not seen a doctor within the last year, because the prescribed treatment was working and 59% said that their headaches had improved. Conversely, 26% had lapsed because they thought there was nothing the doctor could do for their migraines, 20% said that their doctor did not help them and 15% said that their doctor was not interested in headache [9]. Another study showed that reasons for not seeking medical advice included statements like the following: “it’s only a headache” (28%), “over the counter treatments work for me” (32%), “the doctor would not be able to do any more for me” (10%) or “previous visit to a doctor was unsatisfactory/treatment did not work” (6%) [10]. Sixty-five percent of migraine sufferers from the US, the UK, Germany, France and Italy believe that not enough is being done to help them [11]. A focus group study in the US found that migraine patients were interested in understanding their condition and in securing relevant information about migraines, as well as obtaining pain relief. Furthermore, the patients desired collaborative relationships and wanted a team approach to treatment that involved both patient and doctor [12].

These studies have predominantly been based on a survey (quantitative) design and little opportunity has been given to migraine or CDH patients to freely express their points of view. Qualitative research addresses these limitations and increases understanding of the headache patients’ perceptions. It is important to conduct more research into the patients’ perceptions of migraine and CDH patients’, as this is an under-researched area. Qualitative methods are suitable for investigating areas that have not yet been adequately investigated and thus present an appropriate methodology for this type of study. The data presented in this article are part of a broader study, which aimed at gaining insight into the patients’ perspective of migraine and CDH and their management. Findings on the patients’ decision-making for migraine and CDH management have already been published elsewhere [13]. The length of the interviews and the richness of the data meant that the findings could not be fully presented in one article. Thus, the aim of this article is to shed more light on patient’s perceptions and their experiences of headache. Themes presented in this article add and relate to, and give further details of the themes described previously.

Methods

Recruitment, data collection and analysis were carried out simultaneously by the first author (MP), unless stated otherwise, in accordance with the grounded theory methodology [14]. Ethical approval was obtained from the University of Surrey Ethics Committee. The methods have been described in further detail elsewhere [13].

Sampling

A purposive sample of adult patients, who had suffered from migraine according to International Headache Society (IHS) criteria [15], were recruited in Surrey (UK) by theoretical sampling [16]. Participants were recruited through personal contacts (MP and MM), posters in 2 local supermarkets and letters to 20 members of the Migraine Action Association. Thirty-nine participants had been in contact with the researcher to obtain a final sample of 15 participants. Due to the high frequency of their headaches (>15 days per month), 5 participants were classed as suffering from CDH. Dissimilar cases were recruited to reflect a range of personal characteristics based on gender, socio-demographics, age, headache-related disability and consultation status. The purpose of recruiting dissimilar cases was to ensure that the findings were applicable to the wider population of headache sufferers, and not necessarily for generalisation to the wider population. Headache-related disability was assessed by the Migraine Disability Assessment (MIDAS) questionnaire [17]. MIDAS scores of 0–5 signify ‘minimal or infrequent disability’, scores of 6–10 ‘mild or infrequent disability’, scores of 11–20 ‘moderate disability’ and 21 and above ‘severe disability’. Consultation status was determined according to Lipton and Stewart [9]. Patients who had never consulted a physician about migraine were classed as ‘never consulter’. Patients who had consulted within the last year were classed as ‘current consulter’ and those who had not consulted for more than one year were classed as ‘lapsed consulter’ [9]. The participants’ characteristics are described in Table 1.

Data collection and analysis

Data were collected by semi-structured, individual and tape-recorded interviews (n=14). Based on recent migraine literature, a flexible interview guide was devised (Table 2 for initial interview questions). As part of the verification procedure, the interview guide was further developed to include previously raised issues and emerging concepts [14].

Interviews were arranged to the participants’ convenience, at their homes, work place or on campus at the University of Surrey. Interviews lasted up to 2 h with recording time averaging 1 h (range 50–90 min). The first interview served as a pilot interview and was not included in the analysis. HAS and VV read interview samples to assess interview technique and content. Interviewing finished with data saturation.

Table 1 Patients' characteristics

| Patient | Age | Gender | Diagnosis | MIDAS score | Consultation status |
|---------|-----|--------|--------------------------|-------------|---------------------|
| 1 | 38 | Female | Migraine, TTH | 17 | Never consulter |
| 2 | 24 | Male | CDH | 47 | Current consulter |
| 3 | 58 | Female | CDH | 21 | Current consulter |
| 4 | 52 | Female | Migraine | 5 | Lapsed consulter |
| 5 | 55 | Male | Migraine | 3 | Lapsed consulter |
| 6 | 38 | Female | Migraine, TTH | 5 | Lapsed consulter |
| 7 | 28 | Female | CDH | 15 | Current consulter |
| 8 | 34 | Male | CDH | 18 | Current consulter |
| 9 | 60 | Female | Migraine | 14 | Current consulter |
| 10 | 56 | Female | Migraine, TTH | 20 | Lapsed consulter |
| 11 | 48 | Female | Migraine, history of CDH | 6 | Lapsed consulter |
| 12 | 41 | Male | Migraine | 0 | Lapsed consulter |
| 13 | 24 | Female | CDH | 17 | Current consulter |

TTH, tension-type headache

Table 2 Initial interview questions

| |
|---|
| How would you describe your migraines/headaches? |
| How do your migraines/headaches affect your everyday life? |
| How do you treat your migraines/headaches? |
| What are the reasons for using this treatment? |
| How satisfied are you with your treatment? |
| What do you expect from migraine/headache treatment? |
| Who gives you advice about your migraines/headaches (who do you consult)? |
| Tell me more about talking to your GP about your migraines/headaches. |
| What are the reasons for consulting/not consulting your GP? |
| How satisfied are you with your migraine/headache consultations? |
| Who/what else do you think may be able to help with your migraines/headaches? |

Interviews were transcribed verbatim and prepared for analysis in QSR NUD*IST5, a qualitative software package. All authors and an independent researcher were involved in the analysis to reduce bias of the coding and the emerging taxonomy. A coding guide, devised by MP and HAS, was used to standardise coding. To begin analysis, the first 5 interviews were summarised (by MP, HAS, VV and an independent researcher). Secondly, the interviews were coded sentence by sentence to give an initial coding scheme (MP, VV and an independent researcher). No notable differences were found between the coding of the different researchers. The third stage of analysis involved comparing similar and different codes to group the codes into a hierarchical taxonomy to form concepts and theories. These concepts and theories were based on theoretical memos and discussions between the authors. The remaining 8 interviews were used to verify the coding scheme and refine the emerging taxonomy and concepts. First, a summary of the con-

cepts and later detailed definitions, descriptions and interpretations of the main concepts were discussed between all authors.

Results

Three main themes were identified: headaches, headache impact and headache as a health issue. The theme entitled 'headaches' was further divided into 'pain and other symptoms', 'differentiating between different types of headaches' and 'perceptions of headaches as barriers and facilitators to care'. The patients' perceptions, described in relation to these themes, were not static, but evolved over time, depending on the participants' experiences of headache and treatment.

Headaches

This theme focused on the participants' perceptions of their pain and other symptoms, their differentiation between different types of headaches and the influence of their perceptions on management. This theme illustrated the severity of the participants' headaches and particularly migraines.

Pain and other symptoms

For most participants, pain was the dominant feature of their headaches. To help assess the severity of pain the

participants explained their pain severity, their experience of the pain and how the pain developed over time (within an attack) and changed over the years (between attacks). Pain and migraines could be present upon waking up in the morning or could gradually build up during the day. Pt 10 explained:

“...the first thing that I am aware of, it’s like somebody’s put a knife through my head. The pain is so intense that for several seconds I don’t ever open my eyes, in the hope that I’m just dreaming about it...”

Symptoms, other than pain, were also perceived as distressing and sometimes as more upsetting than the headache pain. Pt 12 described:

“...the thing that upsets me the most in a really bad one [migraine], I lose all coherency. I actually don’t know who I am or what anything is and just sounds and colours and brightness then really upset you...”

Differentiating between different types of headaches

The participants all suffered from IHS migraine, and 9 participants also had other headaches, such as daily or near-daily headaches (n=5) or tension-type headaches (n=3). The participants outlined the differences between those headaches. Knowing the difference between headache types was important in decision-making for treatment. Migraines were mostly associated with severe, throbbing pain, nausea and aura symptoms. Other headaches were described as not interfering with daily activities and as being treatable with simple painkillers. Pt 2 said that with a headache:

“...there is not a wide variety of symptoms as with the migraine. There seems to be less symptoms with the headache. It affects [me] less, so obviously the severity is less. And the way that the headache develops, I would say is different to the way the migraine develops...The migraine almost always begins at the back of my skull and works up and forward into my eyes. The headache...just materialises on the top of my head and stays there, it doesn’t really affect anything else. It can usually be dealt with in half an hour to three-quarters of an hour with painkillers...”

Most, but not all of the participants felt confident about differentiating between their headaches. However, Pt 13 felt unsure about her diagnosis:

“...I’m not very good at necessarily differentiating between the migraine and the bad tension headaches... I always think ‘oh, no I don’t suffer from migraine’, but the doctor seemed to think that the way I was describing them that it was more migrainous. I guess I have never been a hundred percent certain of the differentiation between the two...”

Perceptions of headache as barriers and facilitators to management

The type of headache and particularly pain severity were often perceived as a cue for using medication, thus constituting a facilitator to care. When the pain and its severity were the type of pain and severity experienced during previous migraines, the participants took medication to stop the migraine from developing to its maximum severity. Here Pt 3 explained how her past experience shapes her current headache management:

“...I can keep it quite moderate, if I get the tablets quick enough.... I’ve learned to carry the tablets with me. If I know it’s going to be a migraine and I’ll take the tablets quickly. But I do get them really very bad...”

However, the participants’ perceptions also sometimes constituted a barrier to management. The participants sometimes did not accept or doubted some of the characteristics of headaches, such as headaches recurring monthly or even near-daily, or headache severity. These participants expressed hope or optimism that the headaches would not return or resolve without active treatment. Pt 1, who has never consulted for her migraines, believed that her migraine may not recur:

“...I think ‘oh, I haven’t had a migraine for two weeks, maybe they won’t come back’, optimism...”

Similarly, Pt 13 described how her doubts about her headache severity influenced her consultation behaviour:

“...when I don’t have any pain, I then start disbelieving whether it was really as bad as I thought it was... because I could just get on with life and have a couple of weeks and I think ‘yeah, fine no problem’. And then it would hit me again, and I would think ‘oh yeah, it really is that bad’... it was almost like I was disbelieving myself that I was ill or that it was a serious enough problem to look into it...”

In contrast to the participants who were in denial about their headaches, some participants experienced worry and even fear. Worry occurred at the onset of the headaches and was related to a sudden onset, the lack of understanding of symptoms or the worry of a more sinister condition. Participants who were familiar with migraine symptoms, either through a family member or friend, rarely expressed worry. Pt 7 outlined her fear:

“...my vision’s going, it’s scary and I don’t understand...”

Similar to denial, worry influenced the participants’ management behaviour. Worried patients searched for reassurance by consulting other people, most often their general practitioner, for a diagnosis and explanation of the problem and treatment. Thus, whereas denial frequently induced passive behaviour, worry on the other hand induced active behaviour. Pt 7 consulted the doctor because:

“...it was just reassuring, to find out if he could explain what I had, why it was doing it, sort of reassure me that other people had [it]. There are sort of ways in managing it, controlling it, and there [are] either preventatives or over the counters that you can take. Yeah, and mostly sort of reassurance I think, ‘cause it’s just so unknown, at the time it was unknown...”

Headache impact

Participants’ perceptions of impact illustrated suffering and put the magnitude of suffering into the context of the participants’ lives. Headache impact was mainly described in terms of disability, i.e., the participants’ inability to carry out their everyday tasks. All aspects of the participants’ lives had been affected by their headaches, including their work, family and social lives (leisure activities, holidays). Disability was seen as personal to the patients, and referred to limitations to the participants’ everyday activities, such as work and family life, because of headaches. Pt 10 described how she tried not to let migraine affect her life:

“...last year I was to go to an open-air concert, it was Mozart, who is my favourite composer. I woke up that morning with migraine and I just couldn’t believe it. And I thought ‘I’m going... if I have to crawl there on all fours’. I did go and I sat listening to this music with my head pounding. I’d been terribly sick in the morning. But I just could not miss it, but in the interval, I admitted defeat and my sister drove me home...”

Headache-related disability went beyond the impact on the headache sufferers. The participants’ headaches also had an impact on other people, including their families, friends and work colleagues. These people have to help out when the patients were unable to carry out their tasks. Pt 1 described the impact of her migraines on work and family:

“...there is this fear that if I get [a migraine] I’m gonna have to dive off [work] and I won’t be able to fulfil duties. It’s a disaster at home, because I just can’t do anything... I just have to lie down and the children just have to play and crawl around me... Mummy just can’t deal with them or do any housework or do anything... My husband just pitches in when I get one...”

Impact was a relative concept that was influenced by pain severity and headache frequency. More painful headaches usually led to greater physical disability, and less painful, but more frequent headaches usually were more distressing as described by Pt 14:

“...I get really long drawn out ones as well. But they are the ones that bother you the most because you feel like

that all the time and you just get sick of it... I have the constant thing all the time. But at such a level that it doesn’t affect me working...”

The relativity of impact was further demonstrated when participants with similar pain severity and headache frequency did not describe the same impact. The participants’ perceptions of impact varied depending on the participants’ commitments (work and family), their belief in their ability to cope and their ability to fit their lives around their headaches. Participants who believed that they were able to cope and who were able to fit their lives around their headaches, perceived less disruption to their everyday lives and activities and tended to be more accepting toward their headaches. Pt 14 describes how he adapted his life to his headaches:

“...I’ve made my own little world and I’m so busy and it’s all in one place. I haven’t had to face it [getting treatment]... I put up with the stress it [headaches] caused me...”

Headache as a health issue

The theme of headache as a health issue related to what headaches meant in terms of health. The participants assessed what headaches meant as a health problem, as well as the meaning of headache within a wider health context. Headache was perceived to be a health issue, although not necessarily an illness. The refusal of some participants to acknowledge headaches as a problem or an illness meant that the participants perceived headaches as a low priority health issue. This denial often occurred before or soon after onset of the headaches or when headaches were believed to have little impact.

By comparing headaches to other illnesses, the participants put headaches into a wider health context. The participants related their experience of headaches to their own experiences of illnesses other than headaches, other people’s experiences of illness or illness in general. Mostly, participants related headaches to illnesses that they perceived as more serious, and consequently they played down headaches and headache impact. This made it easier for the participants to accept their headaches. Pt 9 felt lucky for ‘only’ suffering from headache:

“...a friend of ours had a stroke. I’m amazed really, I got to sixty and I’ve not had anything like that... So I’m really lucky in lots of ways. I just have a few headaches, that’s nothing...”

Not acknowledging headaches as a problem already indicated that the participants gave low priority to headaches as a health issue. This finding was reinforced by the participants’ beliefs that headaches were less serious or important than other health problems. Perceiving

headaches as low priority influenced the participants' management behaviours, as outlined by Pt 1:

"...If I had a breast lump or something like that, something like that, I'd go straight there [GP], because I know what it is and it needs sorting out. But migraine doesn't fit into that category of absolutely needing sorting out desperately..."

Still, some participants had other views and they considered their suffering related to headaches worse than their suffering related to other illnesses, even life-threatening illnesses such as cancer, as described by Pt 10:

"...when people say to me 'oh my goodness me, you've had breast cancer, how awful'. I said 'it was nothing, it was nothing in comparison to my migraines'..."

Discussion

Three main themes of the patients' perceptions of headache had emerged from the interview data: headaches, headache impact and headache as a health issue. The theme entitled 'headaches' was further divided into 'pain and other symptoms', 'differentiating between different types of headaches' and 'perceptions of headaches as barriers and facilitators to care'. This study adds to the current literature by giving insight into the patients' perspective of headache and by highlighting the influence of the participants' perceptions on their management behaviour. Sampling aimed to recruit dissimilar participants, to make the findings applicable to the wider headache population. However, the small sample size (13 interviews included in the analysis) and the nature of qualitative analysis mean that qualitative findings are limited in their generalisability. Thus a further step into the investigation of the patients' perceptions of migraine and CDH would be to assess whether these qualitative findings are generalisable to the wider headache population. This can be achieved by designing a survey based on these qualitative findings and by subsequently combining and comparing the qualitative and quantitative findings. A survey based on the qualitative findings of patients' migraine and CDH management has already been carried out and these quantitative findings will be published elsewhere.

Within the theme of headache, the participants revealed their perceptions of their headaches and how these perceptions influenced their management. Participants who suffered from more than one type of headache described how they differentiated between various types of headaches. The assessment of whether a headache was a migraine or not was important in the patients' decision-making for treatment. Other factors involved in the patients' decision-making for manage-

ment were headache pain (type and severity) and other symptoms. These findings have been supported by another qualitative study, which investigated patients' decision-making of taking sumatriptan. It was found that at the onset of head pain, participants actively compared their symptoms with a 'migraine template' that they had developed from past experiences [18]. Factors that aided the participants in judging whether a headache was indeed a migraine were the nature, intensity, location and course of pain, the exposure to migraine triggers, presence of associated symptoms and the presence of associated cognitive factors.

The participants' descriptions of their headaches and headache impact link to both the themes of headache (for the description and impact of the headaches) and evaluation described in a previous article on this study [13]. Evaluation described how the participants used their perceptions to assess headache severity and make their management decisions, whereas this article focuses on reporting the actual perceptions. This theme indicates that they perceive their migraine and CDH as a serious problem. However, the participants' perceptions of headaches within the wider context of health conflicted with their perceptions of headaches. The participants perceived headaches as less serious than other illnesses and gave low priority to headaches as a health problem. These perceptions may help to explain the low levels of consultations for migraine [19], despite the high levels of disability [20]. Patients may think that their headaches are severe and disruptive to their lives, but at the same time consider them not a serious enough problem to bother the doctor with.

The results of this study show the high impact of migraine and CDH on the participants' lives. Impact emerged as a relative concept in relation to other diseases, pain severity and headache frequency, as well as social and work commitments. In terms of aspects of life affected, a focus group study in the US revealed the areas of life that migraine patients perceive as most problematic in living with their headaches [12]. The participants described effects on social functioning, family functioning, work and relationships. Similarly in this study, the participants described disability in relation to work, family and social lives. Quantitative findings confirm that migraine and CDH have a significant impact on the sufferer due to disability [5, 21]. The majority of migraine patients suffer at least some disability [20] and patients with transformed migraine suffer even higher levels of disability than patients with episodic migraine [7].

The findings of this study indicated that the patients' perceptions of headache influence headache management, as the patients' perceptions act as barriers and facilitators to management and the decisions on how to manage. Thus, the patients' perceptions are part of the evaluation

process within the patients' decision-making [13]. Another study revealed that the patients' perceptions of their abilities to control headaches (self-efficacy) and the patients' belief that factors that influence headaches are within their control (locus of control) independently explained the variance in headache-related disability in a sample of headache patients [22]. Patients who believed they could prevent and manage their headache (higher self-efficacy) also believed that the factors influencing their headaches were potentially within their control (higher locus of control). In addition, self-efficacy scores were positively associated with the use of positive psychological coping strategies to prevent and manage headaches, and negatively associated with anxiety. Positive coping strategies were, for example, attempts to reduce muscle tension, cognitive restructuring or coping self-statements. Thus, self-efficacy appeared to be a determinant of the patients' efforts to cope with headaches and headache-related disability. However, the participants within this study were all tension-type headache sufferers (90% of whom suffered more than 15 headache days per month), and 29% of patients had an additional diagnosis of migraine.

Headaches remain under-diagnosed and under-treated [23]. Strategies have been proposed to improve headache management. Disability tools, such as Migraine Disability Assessment (MIDAS) [17] and Headache Impact Test (HIT) [24] have been developed and a care approach based on disability assessment (stratified care) [25] has been tested quite effectively. Although shown to be useful, these strategies act at the clinical level, and the majority of patients do not consult their doctors about headaches [19]. Thus, it is necessary to gain insight into the patients' actions outside physician consultations. The findings of this study provide an increased understanding of the

patients' perceptions of migraine and CDH and show how the patients' perceptions influence their management behaviours. Management of migraine and CDH can only be improved in collaboration with the patients. Patient involvement in the care in their chronic illnesses, and patient–doctor collaboration are viewed as a strategy for managing chronic diseases in the 21st century [26]. Education of headache patients has been shown to positively improve quality of life [27]. Thus education programmes to influence the patients' perceptions of headache (by minimising the barriers and maximising the facilitators) may be a suitable approach to improve migraine and CDH management.

Conclusions

This study reveals the patients' perceptions of their migraine and CDH. The participants gave descriptions of their headaches that indicated the seriousness of their condition, as well as the impact these headaches have on their lives. However, in the wider context of health, the participants mostly found their headaches a less serious problem than other health issues. The study also showed how the patients' perceptions influence their management behaviours. Patients may need to be educated and empowered to maximise the potentials of patients as a resource to self-management and to bring about the maximum benefit from the patients' efforts.

Acknowledgements The authors would like to thank Dr. Inez Bandell-Hoekstra for triangulation and Professor Ian Robbins for proofreading. The study was part-funded by AstraZeneca Pharmaceuticals (UK) and the Migraine Action Association (UK).

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