

Study	Adelman et al, 2000⁸	
Aim	To assess migraine sufferers' choice and use of physicians, their experiences in obtaining an accurate diagnosis, and their current treatment practices. Intended to provide physicians a better understanding of their patients' need and behaviours, which will lead to better overall disease management.	
Population	801 people with migraine (IHS criteria) recruited from a consumer database mail questionnaire (diagnosis confirmed by phone screening) in the USA.	
Methods	Telephone questionnaire containing 64 questions. Several measures were open-ended queries which allowed for spontaneous responses. The majority of the reporting in the study is descriptive statistics only. Open ended question results are grouped into logical categories.	
Themes with findings	<u>Sources of information</u> [Poor quality study. Only information directly relevant to the question on patient information and support reported here].	<p>When asked if they felt they had the most current information about treating their migraine, most answered 'no.</p> <p>Current consulters most often relied on their physicians as their source of information, lapsed consulters and non consulters most often relied on magazine news stories for their migraine information.</p> <p>The type of information they wish they had known earlier and think other migraine sufferers might find useful to know was most often related to medication.</p> <p>34% said they would like to have more information on medications, such as what new prescription medication was available and what worked best.</p> <p>20% felt seeing a physician for a diagnosis and/or treatment was important.</p> <p>14% felt that information about other treatments was important, such as how bed rest in a dark room can help a migraine sufferer.</p> <p>12% believe information related to the cause of migraine is important to know, especially what can trigger a migraine and that migraine can be hereditary.</p>
Limitations	<ul style="list-style-type: none"> • Structured interview – not clear how many questions were open ended. • Interview by telephone, including confirming diagnosis of migraine according to IHS criteria. May lead to doubt in diagnosis. • Descriptive statistics only used, no formal qualitative analysis. 	

Study	Belam et al, 2005 ⁶⁶	
Aim	<ul style="list-style-type: none"> To develop a research partnership between migraine sufferers and healthcare professionals who had an interest in the area with the objective of synthesizing tacit and explicit knowledge in the area. To identify and raise awareness of what it is to suffer from migraines from patients' perspectives, in order to improve the management of migraine. To inform the development of a local primary care headache intermediate care clinic and contribute to the dialogue of how headache services should be delivered. 	
Population	8 patients with migraine who had attended an intermediate care headache clinic in the UK. Age range 30 to 61. 6 women and 2 men. Headache impact test (HIT) disability score ranged from 64 to 80. (HIT score reflects the impact of headache on daily activities with a score over 56 indicating a 'substantial impact'.	
Methods	<p>Interviews were carried out by two headache patient researchers based around a question framework relating to key milestones in the headache journey as identified by patient researchers. Modified into focused conversations. Interviews carried out at a health centre with GP researcher available for support. Interviews were taped but not transcribed. Patient researchers were recruited from the same headache clinic, advertisements in the local press and word of mouth and through a migraine organisation. A core group of 5 patients were selected and formed a research team with 3 professionals: a clinical psychologist; a GP who led a local headache clinic; and a research manager who administered the research unity of the general practice where the project was undertaken.</p> <p>There was a debrief after each interview followed by a process of consensus qualitative data analysis at a later date. The research team listened to each tape as a group. Key statements relevant to the research focus or meaningful to a team member were transcribed and grouped into categories based on group discussion about their meaning. The categories were collectively reviewed, cross-references, refined and defined into core themes with typical quotes for each theme.</p>	
Themes with findings	<u>Impact on life (everyone is different)</u> Three aspects were identified:	Physical and psychological impact – all participants identified severe impact on the physical side of their life. Accompanying thoughts of death due to physical impact were thoughts around suicide. There were other physical and psychological implications other than pain.
		Impact on family and social life – the impact of migraine extends beyond the individual to family, friends and colleagues. Study reports that many employers are not sympathetic
		Impact on career – migraine impacts upon career choice and development.
		All patients researchers and participants emphasized the personal and individual nature of migraine. It is recognised that each patient experiences the themes differently.
		A recurring theme is that the impact of migraine is not understood by non-sufferers.
		Metaphor that emerged during the research was "handling the beast". Produced by one of the patient researchers during the latter stages of analysis and resonated strongly with all researchers and participants during feedback of our findings.

Study	Belam et al, 2005 ⁶⁶	
	<u>Making sense of the problem</u>	There was a need to understand what was happening and to place the problem in the context of their lives.
		A recurring theme was the value of talking to others, sharing experiences and exploring meaning.
		All participants and patient researchers found the opportunity of talking to a healthcare professional with an interest in the subject valuable.
	<u>Putting up with it</u>	The majority of migraine sufferers are not under regular medical care and are fatalistic about their problem. (The reasons for this not explored in this study).
	<u>Doing something about it</u>	Participants engaged in a great deal of self-help, both in terms of managing their lives and looking for remedies, particularly within the field of complementary medicine. Self-help was frequently a result of poor experience within the medical service. In many cases, patients felt that GPs and other doctors did not take the condition seriously and that they were unhelpful.
		The experience was not all negative and we were able to identify some positive benefits particularly from the intermediate care headache clinic that all participants had attended.
		An important theme was the advice to other sufferers to read up about their condition before they go to the doctor.
Overall the advice to doctors was to take the condition seriously and sympathetically, acknowledging that migraine is more than just a headache.		
		The recurring theme was that the medical profession does not address the needs of sufferers adequately, but that satisfactory outcomes can be achieved by delivering care from a doctor with a special interest in the area.
Limitations	<ul style="list-style-type: none"> • Only one method of data collection used. • Interviews weren't transcribed and study does not state in detail the methods used to code or identify themes. Authors recognise a lack of rigour in the traditional methods of qualitative analysis but state that the consensual, reiterative methodology used including stakeholder brings different insights and yields a valuable approach that traditional research may have overlooked. • All patients are from an intermediate care headache clinic – the impact of their headache was greater than the population presenting to primary care. • Patients acting as researchers interpreting interviews could introduce bias. 	

Study	Henderson 1999 ³⁶⁸	
Aim	To illuminate the experiences of women living with migraine as it relates to the impact on their quality of life.	
Population	20 women aged 26-45 with migraine (according to ICHD criteria) in Australia. Participants identified through networking with existing support groups established by the Australian Brain Foundation and also from members of groups which had been disbanded.	
Methods	Semi-structured, informal style interviews. Interviews were taped and lasted approximately 1 hour. Interviews transcribed, then tapes were erased. All transcripts were anonymised. Follow up telephone interview lasting approximately 15 minutes to clarify some aspects or issues and validate the emerging themes. Ethnographic data analysis methods used: Notes rewritten, coded and compared. 1 researcher involved. Themes derived.	
Themes with findings	Recognition of migraine as a biological disorder	All except 2 reflected a tendency to blame themselves. Health professionals and others in the community tended to reinforce this concept.
	Inadequate pain relief	Effective pain relief was the most important result women hoped to receive from treatment in order to decrease the severity and frequency of migraines. Pain resulted, in the majority of cases, with a total lost of time and activities.
	Physical and social incapacity	Participants reported markedly decreased physical functioning, with many suffering total incapacity and bed rest. Participants also reported that migraine interfered with their social functioning in a profound manner. There was a strong feeling among many women that other people did not understand their migraine as a valid illness.
	Changes in work role and self esteem	Many were forced to give up work, work part time or work from home. Some experienced a total loss of career.
	Uncertain future	Concerns regarding the unpredictability of the nature of migraine in relation to severity and frequency, and the threat of it being a long term and recurrent illness with no relief or conclusion, excepting between attacks. Long term planning was deemed to be impossible mainly because of the unpredictability.
	Isolation	Began with the process of responding negatively to the chronicity of pain and disability when they who relatives doubted the reality of body pain, blamed the victim and minimised the need for help. Isolation was characterised by negative interactive processes that filled women's lives with unrelieved pain, loneliness and despair. However, many of the women described experiences of shifting their focus to development of coping mechanisms.
	Stressful emotions and development of coping strategies.	Most commonly expressed emotions are anger, frustration, despair, depression, anxiety, acceptance, new hope and determination. The women focussed on fulfilling their lives despite the limitations imposed by migraine. They attempted to define themselves through their own choices and values rather than the migraine or negative perception of others. The most frequently used category of coping was optimistic, followed by self-reliant, supportive, confrontive,

Study	Henderson 1999 ³⁶⁸	
		<p>evasive, and finally emotive. Participants viewed their migraine as a burden, threat or challenge.</p>
	Dissatisfaction with healthcare	<p>An overwhelming response. Characterised in 2 major ways: a lack of understanding and support coupled with ineffective treatments; a lack of education and information combined with little or no help in the development of coping strategies.</p> <p>Little attention has been given to the active role many patients assume when seeking help. Each woman referred in some way to the part she played in actively seeking help. All except one sought help from professional and non-professional healers.</p>
	Lack of understanding and support	<p>Many complained of a lack of understanding and support by health professionals and felt that migraine was not viewed as a valid illness.</p> <p>According to the participants the influence exerted by healthcare professionals was often experienced negatively.</p>
	Lack of information, education and development of coping strategies.	<p>All were frustrated by lack of adequate information and explanation of migraine and its treatment.</p> <p>They stressed that no attention was directed towards coping strategies designed to address the difficulties incurred in living with this disability.</p> <p>All expressed a desire to become more informed about their illness and its management.</p> <p>The found it difficult to locate sources of information, and health professionals were described as giving no guidance or direction to the sufferers.</p>
	Need for education programs for health professionals and the community	<p>Participants perceived there was a general lack of knowledge and understanding of the biological disorder of migraine and its symptoms, but also the psychosocial and cultural aspects of this illness.</p>
Limitations	<ul style="list-style-type: none"> • Only one researcher undertaking interviews and interpreting themes • No quotes given. • Role of the researcher and setting not stated. No patient details stated except for age range. 	

Study	Loder et al, 2005⁵¹²	
Aim	To gain a more complete understanding of cluster headaches	
Population	8 cluster headache patients who were of had been receiving treatment in the Spaulding Rehabilitation Hospital Headache Management Program in the USA.	
Methods	Mailed questionnaires with some open ended questions. Spelling and punctuation were corrected when necessary to improve readability and abbreviations spelled out in full. Potentially identifiable information was deleted or disguised. Otherwise, no changes were made to the choice or order of words. Only selected representative or especially informative answers or portions of answers were included in report.	
Themes with findings	<p><u>What would you like to say to the doctor</u></p> <p><u>[Poor quality study that does not present a thematic analysis. Only information directly relevant to the question on patient information and support reported here]</u></p>	<p>Positive view of 2 helpful specialists: “Both listened intently to what I had to say as I described my symptoms. Both discussed their diagnosis in detail while seeking my input and comment. Both included me in developing an appropriate course of action, explaining pain models and alternate treatments. I always felt I was being listened to, taken seriously, and treated with dignity and respect. I was convinced that my headaches were being addressed by knowledgeable and competent professional, focusing on my problem.”</p> <p>Suggestions: “I would suggest having the person’s family come in to talk with the doctor or clinic because that can be a source of stress at home... I wish my husband had come in with me to the doctor appointments early on. I really did feel I was going out of my mind... feeling out of control is scary and it is important to recognize that”.</p>
Limitations	<ul style="list-style-type: none"> • No details of participants other than their diagnosis. • Mailed questionnaire only. • No thematic analysis. • Only selected responses reported, states that these were the representative or especially informative answers. 	

Study	Meyer 2002⁵⁵⁷	
Aim	To explore, describe and analyse the process of vigilance in women who had migraine headaches to develop a substantive theory of the phenomenon.	
Population	22 females >18years (range 18-61) with migraine in the USA.	
Methods	<p>Purposive and theoretical sampling used for selection of participants. Purposive sample of 9 women of the researcher's acquaintance initially asked to participate. As the theory began to develop, theoretical sampling used and subsequent participants selected to help fully define emerging categories. Semi-structured interviews. Data collection and analysis proceeded simultaneously. Transcripts of taped oral interviews.</p> <p>Initial interview questions were open ended and asked about: background to migraines, when they started; what a typical headache is like; how participants felt at the onset of a migraine; how participants recognised it as migraine; how participants decide what to do if they think a migraine is likely to start; how participants know if what they decided is working; things participants do or don't do because of migraine; how they take care of their migraines; any other experiences.</p> <p>Only appears to involve one researcher in interviews and primary analysis but peer debriefing was used to review coding and categories, interpretations and conclusions were tested with members of the group from whom the data was collected.</p>	
Themes with findings	<u>Owning the label</u>	<p>Women needed to learn to think of themselves as individuals who had migraine headaches. Women typically got a label for their condition with input from others.</p> <p><u>Searching for a name</u> was one sub-category, the other was <u>accepting the label</u>.</p>
	- Searching for a name	Women sought a diagnosis that could explain the frequency and severity of their headaches.
	- Accepting the label	Once they had a name for their condition, they needed to accept it to develop their capacity for vigilance. The woman 'tried on' the label of migraine to see how it fit. They looked for the reinforcement of the label from experts, but it was their own sense of its correctness that led them to accept it. This sense of correctness was reinforced each time the woman successfully named and treated each individual headache episode or identified a trigger.
	<u>Making the connections</u>	<p>The process women used to learn about their personal experience of migraine contained two sub-processes: <u>recognizing the patterns</u> and <u>knowing the options</u>.</p> <p>Required continued use of the strategies of learning from self and others.</p> <p>They continued to get information from experts, other people who had migraines and the media. They saw this as critical to 'keeping on top' of the latest developments in treatments.</p> <p>The more frequent or bothersome their headache, the more actively they attempted to make connections that would allow them to increase control and maximise function.</p>
	- Recognizing the patterns	When women learned to associate internal sensations with the onset of a migraine headache and identifying headache triggers.
	- Knowing the options	The awareness of pharmacological and non-pharmacological forms of treatment.
	<u>Watching out</u>	Women take what they know and apply it to the here and now. There are four subcategories: <u>assigning meaning to what is</u> , <u>calculating the risk</u> , <u>staying ready</u> and <u>monitoring the results</u> .

Study	Meyer 2002 ⁵⁵⁷	
	- Assigning meaning to what is	Women take what they know about their headache and trigger patterns (the connections they have made) and compare it to what they encounter at the present time.
	- Calculating the risk [This section of the paper reports a lot of information specifically about triptans. These data are not reported here]	A strategy used to determine whether the benefits of treatment or trigger avoidance outweighed the negative aspects. The women then used this determination in deciding the course of action. The main issue was the maintenance of function. Sometimes the need to function optimally led to the women to consider intervening more rapidly or to think about going to their second line treatments more quickly. However the intervention itself could be a risk to function. Side effects other than those that affected functioning were also a risk considered. Some women discussed the benefits of avoiding triggers versus their reluctance to give up things they enjoyed.
	- Staying ready	Almost all stated they thought about the importance of keeping their medication available to them. Readiness for encountering triggers was also discussed.
	- Monitoring the results	They needed to be in tune to the sensations that indicated their chosen treatment was working.
	<u>Deciding what to do</u>	
	- <u>Determining actions to be taken</u>	Action to be taken was usually pharmacological. Women talked about a variety of decisions available to them and how decisions changed as circumstances changed. Very few had only one course of action that they always followed.
	- <u>Selecting actions to be avoided</u>	Two basic categories: <u>Things that exacerbate a headache</u> were to be avoided –bright lights and noise, several women thought lying down exacerbated the problem and made a point to try and sit up even if the headache started in the middle of the night, one women avoided bending down to pick something up or walking up steps. <u>Things that might trigger a headache</u> – one woman had eliminated chocolate from her diet; several talked about avoiding alcohol or some types of alcohol (e.g. red wine); some women eliminated perfumes or candle odours, or were very selective about which scents they used; one woman avoided big action films because of the loud noise and flickering lights.
	- <u>Optimising benefits over risks</u>	Women who decided to refrain from drinking alcohol described as “not being worth it”. Other women accepted the risk associated with triggers because they felt avoiding the trigger was worse than the possibility of getting a headache. The acceptance of the risk was especially true when the trigger was inconsistent in causing the migraine.
	<u>Acting to maximise function</u>	
	All of the previous steps in the cascade led to this point. Women maintained vigilance because it allowed them to choose actions they believed would maximise their functioning. After implementing a course of action, the	

Study	Meyer 2002 ⁵⁵⁷
	woman monitored the results and if necessary, the decision process began anew. Action also led to learning about what worked and what didn't. This knowledge reinforces the label and was incorporated into the woman's set of connections for future decision making.
Limitations	<ul style="list-style-type: none">• Unclear how participants were selected. Researcher describes initial 9 participants as "acquaintances" with migraine.• Unclear what setting the interviews were performed in and the role of the researcher.• Only appears to involve 1 researcher in data collection and first analysis.

Study	Moloney 2006 ⁵⁶⁶	
Aim	To obtain the perceptions of migraine experience in the context of perimenopause. In addition to understanding the meaning of the individual experience, the purpose was also to understand common meaning and shared practices across the narratives.	
Population	53 women with migraine aged 40-55 enrolled in 2 consecutive studies in the USA. Study 1 recruited from a health maintenance organisation, study 2 recruited from a university setting, local community and the internet.	
Methods	<p>Study 1: Qualitative interviews, focus groups, paper-and-pencil questionnaires and 6 month daily, primarily quantitative, diaries. Study 2: internet based, with both in-person and phone interviews, similar quantitative questionnaires and online discussion boards that were virtual focus groups. Interviews: open ended questions started with "Tell me the story of your headaches" followed by the use of other probes and clarifying questions as needed. Audio taped 30 to 60 minute interviews. Interviewer also posted open ended questions on discussion boards similar to those used in individual interviews. 8 consecutive 3 to 5 week discussion boards were posted. Interviews transcribed verbatim; discussion board data were cut and pasted into word processing software.</p> <p>Interviews were transcribed verbatim, discussion board data cut and pasted from website into word-processing software. Both analysed using a qualitative software analysis package for organising data. Analysis and data collection proceeded concurrently, creating a circular process that influenced subsequent questions and interpretation of data already obtained. Patterns and themes were identified mostly from the quotes.</p>	
Themes with findings	<u>Changing Headache Patterns</u>	<p>Two major themes: headache patterns; and looking for an answer.</p> <p>Some women were seeking a definite diagnosis.</p> <p>Most had tried a variety of prescription medications and all were looking for non-prescription self-care sources of headache control.</p> <p>One of the reasons commonly given for participating in this research was to learn more about headaches and headache management.</p> <p>Many women described worrying about whether their headaches were related to such causes as a brain tumour or aneurysm; whether they could be the result of problems with wisdom teeth, high blood pressure, or perhaps because of a detached retina.</p>
	<u>Predicting, preventing and controlling headaches</u>	Themes that comprised this pattern were: Is this a migraine or something else?; Identifying triggers; Course of the headache: the lurking migraine; Medications; and I might try... self-care interventions.
	<u>Keeping on the move</u>	<p>Four themes: Working through the headache; Desperation; Keeping my arsenal of medicine; and Having a dirty secret.</p> <p>Having a dirty secret – participants addressed the stigma and guilt of having this problem, which in the past has been perceived as psychosomatic, and which authors reported as still perceived with skepticism by many people. A few women noted that they had never appreciated the severity of their mother's headaches, or how they resented how their mother's headache disrupted family and social activities, until they had migraines themselves. In addition to their own feeling of inadequacy about controlling their headaches, the attitude of others (coworkers, healthcare providers and sometimes family) reinforced the stereotype of a midlife woman with migraines being someone who has given in to a headache when she could control it if she had more will</p>

Study	Moloney 2006 ⁵⁶⁶
	<p data-bbox="936 236 1749 268">power, or of a woman who is using her headaches to avoid responsibilities.</p> <p data-bbox="483 280 2148 408">Healthcare providers received mixed reviews with regard to headache knowledge, treatment and empathy. Many women described caring physicians and nurses who had diagnosed their headaches and supported them, but most also remembered times when they either didn't receive an appropriate diagnosis or help, or when it was apparent that the provider was either too busy to listen to complaints about headaches, or who seemed to think that a headache was not important.</p> <p data-bbox="483 416 1816 448">Several participants said they suspected the most helpful providers were those who seemed to have migraines themselves.</p>
Limitations	<ul data-bbox="533 464 1592 533" style="list-style-type: none"> <li data-bbox="533 464 1592 491">• Not clear how themes were identified or whether more than one person verified the analysis. <li data-bbox="533 504 981 533">• Ethical approval not stated explicitly.

Study	Packard, 1979 ⁶⁰¹		
Aim	To explore the questions: <ul style="list-style-type: none"> • What do headache patients want when they come to the doctor? • What do physicians think headache patients want? • Are they after the same thing? 		
Population	100 outpatients with the chief complaint of headache at a neurology clinic in the USA. <ul style="list-style-type: none"> • Age range 14 to 64 years, 54 females, 46 males. • 23 patients reported this was the first time they had seen a doctor. • Duration of headaches: < 1 month (n=7), 1 month to 1 year (n=20), 1-4 years (n=28), 5-9 years (n=14), 10-19 years (n=13), >20 years (n=18) • No. of doctors seen: 0-1 doctors (n=23), 2-3 doctors (n=41), 4-5 doctors (n=19), 6-9 doctors (n=9), 10-19 doctors (n=4), >20 doctors (n=5) 		
Methods	<p>Questionnaires in two parts were handed out at outpatient clinic until 100 patients had completed the form. In the first part specific information obtained including age, sex, whether this was the first time they had seen a doctor for their headache, how they were referred, how many doctors they had seen previously, duration of headache, whether they had more than one type of headache, did they understand the cause of their headache, how much they believed “nerves” or “tension” were contributing to the headache, did they feel more than one visit would be necessary or helpful, were they worried about a brain tumour, and what they were expecting: total, some or no relief.</p> <p>In the second part patients were asked to rank 12 factors in order of importance on a scale of 0 (was not important at all) to 10 (was most important). At then end, if they had ranked more than one factor as “10” they were asked to put this in order of importance.</p> <p>Also, 50 physicians from various specialities completed a survey as to what they thought patients wanted when they came to see the doctor.</p>		
Themes with findings		Most often selected in top 3	Most often selected first
	<u>Ranked factor</u>	Patients (n=91)	Patients (n=100)
	Explanation of cause of pain	77%	46%
	Medication	20%	0
	Explain about medication (how it works, side effects)	32%	3%
	Treatment other than medication (please indicate)	18%	1%
	Time to ask doctor questions	20%	3%
	A psychiatric evaluation	3%	0
	Doctor willing to follow them for their headache	26%	4%
	Complete neurological examination	31%	7%
	Skull x-rays	8%	1%
Talking to other headache patients in a group	0	0	

Study	Packard, 1979 ⁶⁰¹		
	Pain relief	69%	31%
	Complete eye examination	11%	4%
	<ul style="list-style-type: none"> • Expectations of relief: 31 patients total relief, 67 patients some relief, 2 patients no relief • 43 patients reported having more than 1 type of headache. “Although most patients complained of only one type of headache, some combined them into a confusing blend that they tried to present as a single headache”. • 29 patients felt they understood their headache, 71 did not • 26 patients expressed concern about having a brain tumour 		
Limitations	<ul style="list-style-type: none"> • Unclear whether this is just primary headache though study states “chief complaint of headache”. • Leading questions with the factors for ranking being predefined. There was no possibility for participants to add their own factors of what they want. 		

Study	Peters et al, 2003⁶²⁰ *	
Aim	To investigate patient perceptions and experiences of headache. 1 - Factors involved in the patients' decision making.	
Population	13 migraine sufferers (according to IHS criteria) aged 18-65 in the UK. Recruited from university setting, adverts in supermarkets and members of Migraine Action Association.	
Methods	Semi-structured, individual and tape recorded interviews. 11 open ended initial interview questions. Interviews arranged at the participants convenience in terms of location transcribed verbatim and prepared for analysis in a qualitative software package. All authors, as well as an independent research, were involved in stages of the analysis. No notable differences were found.	
Themes with findings	<u>Headaches, Consultations & Management</u> identified as three main themes for the base data.	
	Management strategies	All described a range of management strategies and self-help measures they had used in the past or were still using. All used several strategies at one time and the combination was individual to every patient.
	The four stages of decision-making	<u>Headache severity</u> , <u>evaluation</u> , <u>decision</u> and <u>behaviour</u> . A complex and dynamic and continuous process that developed over time and operated on a justification and consequence system. Every decision, behaviour and change in migraine severity added to the experience and perceptions of the patient.
	- Headache severity	The diagnosis of the headache types (symptoms, pain severity, frequency duration); the progressive nature of migraine during attacks and over the years and; impact of the headaches (work, family life, social life/leisure activities).
	- Evaluation	Awareness (how to deal with the problem); Assessment (headache severity, experiences of management, outcome and limitations of management); Balancing options with perceptions (Management available – knowledge, Information gathering – from health professionals, family and friends, media, headache societies); Perceptions (Attitudes, beliefs, expectations, satisfaction, preferences).
	- Decision	Specific (related to a specified management strategy); Non-specific (general decisions to headache management).
	- Behaviour	Active and Passive Management strategies (Consultations – doctor or other health professional, Pharmacological – Acute or prophylactic, Non-pharmacological – self-help or alternative therapies).
Limitations	<ul style="list-style-type: none"> • Not clear who conducted the interviews. 	

Study	Peters et al, 2004⁶²¹ *	
Aim	To investigate patient perceptions and experiences of headache. 2 - Patients perceptions of the management of their headache.	
Population	13 migraine sufferers (according to IHS criteria) aged 18-65 in the UK. Recruited from university setting, adverts in supermarkets and members of Migraine Action Association.	
Methods	Semi-structured, individual and tape recorded interviews. 11 open ended initial interview questions. Interviews arranged at the participants convenience in terms of location transcribed verbatim and prepared for analysis in a qualitative software package. All authors, as well as an independent research, were involved in stages of the analysis. No notable differences were found.	
Themes with findings	The patients use of management strategies fitted into five areas:	
	Healthcare use	<p>Focused mainly on consultations with doctors and mainly the GP (although other healthcare professionals also described).</p> <p>For GP's some had low expectations and questioned the GP's ability and interest to treat headaches, to the extent that they did not consult for headaches. Participants who had consulted a neurologist described higher expectations and often a preference for specialist consultations. They were not necessarily more satisfied.</p> <p>Participants thought GP consultations mainly revolved around pharmacological treatments. Little attention was given to issues such as uncovering the causes of headaches, finding a cure and discussing the impact of headaches or non-pharmacological and alternative therapies. These were issues that the participants would have like to discuss with their GPs.</p> <p>When issues other than medication were discussed, the participants were encouraged to return for further consultations, the GP was perceived as helpful and interested.</p>
	Medication use	<p>The participants' perceptions ranged as widely as the number and types of medications used.</p> <p>All expressed preferences for not taking medication, but all had relied on medication for their headaches in the past. Generally the participants found using acute medication more acceptable than using prophylactic drugs. One participant concluded that there was no effective treatment.</p> <p>Patients had low expectations and worry of side effects, some preferred to cope without medication or restricted their medication use.</p> <p>Others found an effective drug and preferred taking that to having a migraine. The reasons to take medication included pain control, restoring the ability to function or the prevention of headaches. Different medications served different purposes.</p>
	Alternative therapies	<p>Although not all had consulted an alternative therapist, the generally expressed an interest in what they had to offer. Frequently it was the cost that prevented them from trying.</p> <p>Those who had consulted gave little description on how effective they were but expressed satisfaction with the time and advice offered by alternative therapists.</p> <p>The participants also used homeopathic and herbal remedies, compared to pharmacological agents they were</p>

Study	Peters et al, 2004 ⁶²¹ *	
		rated as 'natural', 'safer' and as 'not leading to side effects'.
	Social support	<p>Used to complement or further improve the participants' headache management. Received from families, friends, work colleagues and other headache patients.</p> <p>Having people to talk to about headaches, and particularly other headache patients, was considered enjoyable and interesting.</p> <p>Talking to people allowed participants to give and receive support and understanding and to exchange information and gain insights into other management strategies.</p> <p>Getting new information about headaches to learn to better deal with them was considered important. New information was sought through various sources of social support, such as family, friends, work colleagues and other headache patients and the media. Particularly charities such as the Migraine Action Association were thought to be useful since they gave access to the latest developments.</p> <p>Not all participants benefited from social support, for example one was not aware of an association that can provide information on migraine.</p>
	Lifestyle and self-help	<p>Analysis revealed patient as having a central role in their management, and the patients perceived themselves as an essential resource to the management.</p> <p>The participants often thought it was their responsibility to deal with their headaches through self-help and lifestyle changes.</p> <p>Self-help involved taking initiatives and contributing to their own headache management, by gaining information about treatments, selecting their own prescription drugs, and convincing their GPs to prescribe the drugs.</p> <p>Self-help often revolved around triggers and analysis of their own headaches to help find a cause and possibly a cure.</p> <p>Lifestyle management strategies revolved around stress control, getting enough sleep and dietary changes.</p>
Limitations	<ul style="list-style-type: none"> • Not clear who conducted the interviews. 	

* Same study with different sections of the analysis reported.

Study	Raieli et al, 2010⁶⁴⁵		
Aim	<ul style="list-style-type: none"> To assess simultaneously children's and mothers' expectations from medical consultation concerning headache, and paediatricians' opinions about said expectations. To investigate mothers', children's and paediatricians' opinions about symptomatic and prophylactic treatment of headache. 		
Population	<p>100 patients aged 10 to 16 years and their mothers presenting at an outpatient service in Italy for diagnosis and treatment of headache (inside the Child and Adolescent Neuropsychiatry Department) between February 2002 and May 2003.</p> <p>Exclusion criteria: patients with headaches transferred from emergency department; patients with secondary headaches; patients with cognitive deficits who were not able to answer the questions of the questionnaires; patients with serious neurological or medical conditions. Other than patients transferred from emergency department 18 patients excluded: 6 with probable secondary headache, 7 with cognitive deficits, 5 with epileptic seizures.</p>		
Methods	<p>Questionnaires were given to each patient and their mother at the first consultation before clinical evaluation. Questions were selected in 2 ways: some were from previously published studies on similar topics. Studies cited include previous surveys; and others were designed by the authors. The mother and children questions were multiple choice; for every question they had a choice of 1 to 3 prearranged answers. If they desired, they could also signal an order of preference among the answers. Very few subjects chose to do this.</p> <p>Questionnaire also sent to 50 local family paediatricians recruited while attending a continuing medication education programme unrelated to headache. This assessed their beliefs about the reasons why mothers ask for their consultation and what the expectations of children and their mothers are about headache treatment options. The physicians were not referring physicians for the sample of 100 children surveyed so their responses were considered generic.</p>		
Themes with findings	Expectations of children and mothers from the <u>paediatric consultation</u>		
	<u>Children's and mothers' expectations</u>	<u>Children % (n=100)</u>	<u>Mothers % (n=100)</u>
	To be reassured that it is not a serious illness	60	47
	To find out the causes of headache	45	62
	To receive medication for the treatment of pain after its beginning (symptomatic treatment)	21	5
	To benefit from diagnostic investigations (i.e. blood tests, EEG, etc)	0	28
	To be referred to a headache specialist	8	39
	To have a careful medical examination	28	22
	To receive medication to prevent and reduce the number of the attacks (prophylactic treatment)	20	5
	To know the progression of headache in the future	26	3
	Other	0	2
	Expectations of children and mothers from the <u>headache specialist consultation</u>		
	<u>Children's and mothers' expectations</u>	<u>Children % (n=100)</u>	<u>Mothers % (n=100)</u>

Study	Raieli et al, 2010 ⁶⁴⁵		
	To be reassured that it is not a serious illness	54	<u>56</u>
	To find out the causes of headache	54	82
	To receive medication for the treatment of pain after its beginning (symptomatic treatment)	26	7
	To profit from diagnostic investigations (i.e. blood tests, EEG, etc)	2	10
	To benefit from neuroradiological investigations (i.e. CT, MRI, etc)	8	5
	To have a careful medical examination	28	41
	To receive medication to prevent and reduce the number of the attacks (prophylactic treatment)	28	11
	To know the progression of headache in the future	32	17
	To get well	33	3
	Other	3	2
	Mothers', children's and paediatricians' opinions about <u>symptomatic treatment</u>		
	<u>What do you think about drugs given for the treatment of the pain after its beginning (symptomatic treatment)?</u>	<u>Children % (n=100)</u>	<u>Mothers % (n=100)</u>
	It is necessary in the presence of severe pain	68	49
	I'm afraid of them, I prefer not to use drugs	12	12
	Drugs are often useful, but sometimes also dangerous	18	18
	Drugs are never advisable for a young patient	2	2
	If the pain is not too intense, it is better to contrast it only by sleeping	23	23
	Other	0	0
	I don't know	8	8
	Mothers', children's and paediatricians' opinions about <u>prophylactic treatment</u>		
	<u>What do you think about drugs given over a long period to prevent and reduce the number of headache attacks (prophylactic treatment)?</u>	<u>Children % (n=100)</u>	<u>Mothers % (n=100)</u>
	It is necessary in the presence of dangerous pain	35	12
	It can prevent the progression of disease in the future	18	7
	I'm afraid of side effects	8	24
	A long lasting treatment could be dangerous and induce addiction in young patients	14	21
	It is necessary in the presence of severe and long lasting pain	61	37

Study	Raieli et al, 2010 ⁶⁴⁵		
	I don't know if drugs will induce side effects in the future, so I don't want to use them	6	7
	Other	0	0
	I don't know	2	1
Limitations	<p>Leading questions that may raise concerns that children or mothers did not previously have.</p> <p>Study states it represents a very small and highly selected sample.</p> <p>Study also states that the organisational peculiarity of the Italian paediatric health care network may limit a generalisation to other countries</p>		

Study	Rozen et al, 2006 ⁶⁷⁵	
Aim	To better understand what patients want from their preventive migraine medication.	
Population	150 migraine patients presenting at the Michigan Head Pain & Neurological Institute (MHNI). Mean age 49, range 13 to 71 years. All patients had been seen at least 1 previous time to be included in the survey, most had been patients for >1 year. All had prior exposure to migraine preventive therapy.	
Methods	10 question survey carried out over a 1 month period as a consecutive series. Patients asked to rank in order of importance characteristics of migraine preventive therapy.	
Themes with findings	<u>Survey question</u> Your physician involves you in the decision of choosing a headache preventive medication Your physician takes time to tell you the possible side effects of the preventive medication being prescribed A preventive medication that has been reported in the medical literature as highly effective Taking more than 1 preventive drug at the same time if you had a greater chance of reducing your headaches A preventive medication that may increase or decrease your weight A preventive medication that may cause sedation Once daily dosing of preventive medication A preventive medication that has a high risk of side effects but is very effective at preventing migraine The use of natural therapy (non medicine like vitamins and herbs) A preventive medication that has a low risk of side effects but many not be very effective in preventing headache	<u>Mean ranking</u> scale of 1 (little importance) to 10 (extremely important) 8.7 8.5 8.3 8.2 7.3 6.8 6.6 6.2 6.1 3.9
Limitations	<ul style="list-style-type: none"> Study reports that patients were attending a migraine speciality clinic therefore most likely had more difficult to treat migraine compared with the general migraine population. Conversely, this patient population had a significant exposure to preventive medication therefore their insight may be more meaningful than those not exposed to prophylaxis. 	