

Using the common-sense model of illness representations to explore individuals' experiences and perceptions of migraine and its management in the United Kingdom

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Abstract

Objectives: Migraine is considered a chronic health condition that impacts both quality of life and psychological wellbeing. People with migraines use a range of management strategies, which include pharmacological and non-pharmacological treatments. The aim of this study was to explore individuals' experiences and perceptions of migraines and its treatment using the Common-Sense Model (CSM) of Illness Representations.

Methods: Semi-structured, one-to-one interviews were conducted with eleven individuals with a history of migraine to explore their experiences and perceptions of migraine and its treatment. Participants were recruited from across the United Kingdom via convenience sampling using social media advertisement. Interviews were recorded, transcribed verbatim, and qualitative data were analysed using theoretical framework analysis using the CSM.

Results: The three dimensions of the CSM were mapped on to the qualitative data. These were: (i) Cognitive representations of migraine, within five domains: (a) identity of migraine, (b) perceived causes, (c) perceived timeline, (d) perceived control/cure, and (e) perceived consequences; (ii) Emotional representations of migraine relating to (a) migraine specific emotions and (b) emotional representation of the impact of migraine; and (iii) Coping/self-management behaviours, namely (a) self-medicating behaviours and (b) care-seeking behaviours. No incongruous data were found; therefore, no further thematic analysis was required.

Conclusion: This is the first study to apply the CSM to migraine for framework analysis of qualitative data in this way. The findings illustrate the emotional impact of migraine and the range of illness perceptions associated with appropriate self-management. The data will be used to design a questionnaire for quantitative studies to investigate the extent to which these perceptions are generalizable to the wider population of people who experience migraines.

Keywords: migraine; chronic illness; theoretical framework analysis; illness representations; common sense model; self-regulation theory; self-management

Background

Migraine is a chronic neurological condition; it is the third most common acute disease in the world with an estimated global prevalence of 15% [1]. Migraine is described as a reoccurring throbbing pain on one side of the head, which can be severe in intensity and accompanied by nausea or auras [2]. Migraines are typically classified into three distinct types: migraine with aura, migraine without aura and migraine auras without headaches [3]. First-line treatment for managing migraine is pharmacological; treatment guidelines recommend simple analgesics, non-steroidal anti-inflammatory medication, specific antimigraine compounds, or prophylactic treatments [4]. Several non-pharmacological interventions have also demonstrated efficacy in migraine prophylaxis; these include cognitive behavioural therapy, stress management, and mindfulness [5–7].

Despite the availability of a diverse treatment options, migraines remain undertreated in over 50% of patients [8]. Estimates suggest that less than half of individuals who

experience regular migraines consult a healthcare professional to seek advice about treatments [9]. Many individuals prefer to manage their migraines themselves and choose to self-medicate, relying on non-prescription over-the-counter medications (OTC) such as simple analgesics to manage symptoms [10]. A cross-sectional study exploring self-medication for migraine symptoms found that those who delayed treatment were significantly more likely to initially control symptoms using OTC and often postponed taking Triptan medication (a family of tryptamine-based medications which have agonist effects on serotonin 5-HT_{1B} and 5-HT_{1D} receptors in blood vessels) to be confident that their migraine was not just a headache [10]. These findings are supported by the work of James and French [11] who found that individuals were reluctant to take OTC medication unless symptoms were severe.

Leventhal's Common-Sense Model (CSM) of self-regulation [12] can be used to understand the factors that influence medication-taking behaviours in migraine. The CSM

describes how illness perceptions (the emotional and cognitive representations held about a health condition) influence coping strategies and coping behaviours [12]. These illness perceptions are fluid, changing over time as people develop coping strategies (successful or otherwise) to manage their condition. Illness perceptions are centred on five key representations, relating to beliefs about: (i) Identity ‘What is it?’, (ii) Cause—‘What has caused it?’, (iii) Time-line—‘How long will it last?’, (iv) Cure/Control—‘What can be done to cure or control it?’, and (v) Consequences—‘What impact will it have on my life?’. Since the CSM is a framework that describes how cognitive and affective processes shape an individual’s response to illness, it is relevant for understanding how individuals self-manage their migraine symptoms, particularly due to the unpredictable nature of the condition.

Research on how illness perceptions influence self-management or adherence to treatment for migraine is limited. The purpose of this study was to explore migraine and its treatment using the CSM of self-regulation. To the authors’ knowledge, this is the first study to explore the utility of using the CSM to understand illness perceptions in migraine. Adopting qualitative methodology, underpinned by theory, enables a complex understanding of the cognitive and emotional processes that influence how individuals perceive their condition and how they self-medicate in response to migraine symptoms. The aim of this study was, therefore, to use the CSM to characterize patients’ illness perceptions related to migraine.

Methods

This qualitative study used one-to-one semi-structured interviews to explore individuals’ experiences of migraine and its treatment. The COREQ checklist was used to ensure transparency of reporting in this manuscript. The study received ethical approval from the Cardiff School of Sport and Health Sciences Ethic Panel. Participants were recruited via convenience sampling using a social media advertisement (Facebook). The eligibility criteria for the study were that participants must be over 18 years of age, have experienced at least one acute migraine episode within the last 6 months, and be English speaking. Potential participants received an information sheet and a consent form via email, which they were asked to read and sign if they agreed to take part. The target sample size was between 10 and 15 participants; Twelve individuals came forward and were approached for interview of which 11 consented to take part in the study. A benefit of applying a theoretical framework to data collection is that data saturation can be achieved with a smaller sample size; all aspects of the SRM had been addressed after a few interviews. All participants were white, nine were female, and two were male. The age of onset of the first migraine episode ranged from 9 to 23 years of age. Most participants were in the 50–59 years age category ($n = 6$), followed by 40–49 years ($n = 3$), and one each in the 30–39 and 20–29-year age category, respectively. Participants lived in Southeast Wales and Southwest England. Demographic characteristics are shown in Table 1.

Data collection

The design of the interview schedule was informed by the CSM [12] and developed by the research group (D.H.J., R.E., and C.H.S.) with input from two migraine patients. The interview schedule contained 22 open-ended questions across

Table 1. Participant demographic characteristics ($n = 11$).

Participant	Sex	Age category (years)
P1	Female	30–39
P2	Female	50–59
P3	Female	50–59
P4	Female	40–49
P5	Male	20–29
P6	Female	50–59
P7	Female	50–59
P8	Female	50–59
P9	Male	40–49
P10	Female	40–49
P11	Female	50–59

five sections. These were: Section (i) Migraine symptoms, (ii) Cause of migraines, (iii) Treatment strategies for migraine management, (iv) Perception of migraine treatments, and (v) Impact on life. A test interview was conducted to make sure the questions were acceptable and to ensure a logical flow; these data were not included in the analysis. Following the test interview, minor changes were made to the order of questions to enhance the structure of the interview. Interviews were conducted face-to-face with the researcher and participant in a university setting (R.E., female, postgraduate student with experience in conducting qualitative interviews). Interviews were audio recorded and transcribed verbatim with any personal identifying information removed. Length of interviews ranged from 30 to 45 minutes in duration.

Analysis

Anonymized transcripts were transcribed verbatim and analysed (R.E.) using framework analysis [13], where the CSM was used as the underpinning theoretical framework. This approach codes transcripts line by line as applied to the framework’s indexing headlines (e.g. illness representations, i.e. identity, cause, timeline, cure/control, and consequences). The plan of analysis was to examine any remaining data incongruous to the CSM framework for further thematic analysis [14]; however, this was not needed since no further themes were identified. Secondary coding was completed by the research team (D.H.J., C.H.S., S.C., W.N., and R.E.), and any discrepancies were discussed and resolved by consensus to reach the final themes. A reflexive account of the qualitative research process including analysis can be found in [Supplementary Material 1](#).

Results

Table 2 summarizes the mapping of qualitative data to the three dimensions of the CSM. Further details of the mapping of verbatim quotes to the CSM for each participant are presented in [Supplementary Tables 1–7](#).

Cognitive representations of migraine

Identity of migraines

Participants attributed 24 different symptoms to migraine. The ‘core’ features of a migraine were similar across interviews (i.e. nausea, headache, and pain around one eye).

Table 2. Mapping of data to the CSM showing dimensions, domains, and sub-domains.

Dimension	Domains	Sub-Domains
1.Cognitive illness representations of migraine	a) Identity—What is it?	(i) Symptoms attributed to a migraine (ii) Process of self-diagnosis
	b) Cause—What has caused the migraine?	(i) Lifestyle (ii) External stimuli (iii) Emotional (iv) Behavioural (v) Biological
	c) Timeline—how long will the migraine/migraines last?	(i) Length of each migraine episode (ii) Frequency of a migraine (iii) Anticipated stage of life the migraines might cease
	d) Cure/Control—what can be done to cure or control the migraines?	(i) Perception of Pharmacological Treatment (ii) Perception of non-pharmacological treatment (iii) Perception of not treating.
	e) Consequence	(i) Consequences of the migraine itself (ii) Consequences migraine treatment
2.Emotional illness representations of migraine	a) Migraine-specific emotions	N/A
	b) Emotional representations of impact	N/A
3.Coping/self-management behaviours	a) Self-medicating behaviours	N/A
	b) Care-seeking behaviours	N/A

Other symptoms included aura, stiff neck, tense shoulder muscles, and sensitivity to light.

“it is kind of like an exploding head feel and it was always above my right eye” (P1)

“do get a bit of an aura just a little bit of a ball of flashing light” (P3)

All participants were able to accurately identify and label migraine symptoms and made a clear differentiation between a migraine and other types of headaches.

“...think I have a good handle of understanding migraines... whereas a headache is just “a headache, your head hurts, a migraine is much more of a physical thing” (P3).

Perceived cause of migraine

Twenty-four different migraine triggers were identified, and most individuals attributed the onset of their symptoms to more than one trigger. Triggers were categorized into lifestyle, external stimuli, emotions, behaviour, and biological factors.

“They will wait until it is your day off somehow. It is stress related” (P8).

“...using the computer all day or I am really busy and tense, it can turn into a migraine” (P1)

“I put it down to red wine” (P6)

Perceived timeline of migraines

Migraines typically lasted between 1 and 5 days. They were experienced on a cyclical basis with the frequency of ‘attacks’ varying from once a year to more than once a month.

“So, when they kick in they would always last for three days” (P3)

“Not, not so frequently anymore. I would say like one every two months. (P5)

Perceived cure/Control for migraine

Participants considered their migraine to be an incurable condition that would have to be controlled rather than cured.

“I could not imagine it being something that can be cured so that’s why I presume it will be for all my life” (P5).

Beliefs about the controllability of migraines were associated with the behavioural actions used to manage symptoms. Individuals who reported using pharmacological treatments to manage migraine typically believed that using a combination of OTC analgesics and prescribed medication would be effective at managing symptoms.

“I take the medication and rest if I can rest” (P5)

“Normally, I take normal pain killers and then I will take Migrave tablets (P9)

Eight traditional pharmacological treatments were mentioned, which included paracetamol, triptan medication and prophylactic propranolol; however, these were sometimes used in conjunction with alternative medications such as ‘Tiger Balm’ and ‘Fiery Jack’ (herbal-based ointments available in the UK).

“So, I stick a bit of Tiger Balm on or Fiery Jack on it or something like that to try and kill the muscle tightness” (2.10)

Participants described twenty-three non-pharmacological approaches which they used to control migraine symptoms; these included adopting a healthy lifestyle, resting, reducing caffeine, drinking water, and having an Indian head massage. Individuals who perceived benefits from non-pharmacological

approaches to managing their migraines, typically believed that using a combination of these ‘self-care’ behaviours would be effective.

“I have been doing reflexology and umm changing my mattress. Little things like that, because I have not found physiotherapy or medicine have helped in the long term so...” (P1)

Some individuals perceived that nothing has been helpful in curing or controlling migraine symptoms.

“I have learnt over the years pain killers do not work” (P3).

Or perceived migraine as a passing discomfort that does not require intervention.

“...and I think you know the headache is not going to kill me or the migraine, so I just bare my teeth” (P10).

Perceived consequences

Perceived consequences of migraine could broadly be into two domains: the consequences of the migraine itself and the consequences of taking migraine treatment. Migraine pain was described as debilitating and disruptive. Those who experienced persistent pain or fatigue during a migraine episode felt that their cognition was often affected to the extent that they had difficulty engaging in work, socializing and/or family life.

“So, I use to plan in my diary that these were the danger days.....decision making becomes very difficult ...It slows me down hugely. I think much more slowly with one” (P3).

“I have to phone work and say I have got a migraine and I am off” (P6)

“You are unable to do things, running around doing those things, so it impacts on family life as well” (P11)

Participants described the consequences of taking migraine medication. Although medication relieved pain, the side effects from most pharmacological treatments impacted function. Interviewees highlight that medication made them feel drowsy, faint, and dizzy and limited their ability to drive, work, and study. Participants were concerned about the long-term impact that migraine medication would have on their general health.

“Medication that I have to take is so horrible. The side effects are so horrible” (P8)

I do not know the long-term effects” (P10).

Emotional representations of migraine Migraine-specific emotions

Emotional responses towards a migraine were mostly negative, with individuals using words such as ‘scared’, ‘worried’, and ‘fearful’. There were also feelings of ‘hope’ (that they would grow out of it) and ‘happiness’ (at learning how to manage it) and a sense of ‘empathy’ towards others who experience migraines. When describing the ‘first’ migraine,

individuals reported feeling frightened, where symptoms were not recognized as a migraine; this led to concerns about the underlying cause.

“...it was really, really scary I thought there was something wrong” (P5).

Emotional representations of impact

Emotive terms such as ‘alarming’, ‘scary’, and ‘nightmare’ were offered to describe the impact of having migraines on daily living. Frustrations about the impact that symptoms had on work and family lives were evident. The unpredictability of migraine onset was an emotional burden, as interviewees lived in anticipation that the condition could cause disruption to their lives at any point.

“I get quite anxious when I have got one” (P3)

“...it is just not feasible to give up on your life for three days every month” (P3).

Migraine coping/self-management behaviours

Participants described various medicine-taking behaviours. Those who took medication at the initial onset of symptoms also made sure that their migraine medicine was readily available.

“I carry them in my bag. I am prepared all the time” (P4).

Others avoided taking medication until their symptoms became more severe. The cost of purchasing medication was also reported as a reason for rationing medication use.

“...so, I never really tried those because they were really expensive, so I would just try and grin and bear it” (P4).

An approach of trying a non-pharmacological intervention to manage symptoms first was highlighted, where holistic strategies were used; these were changes to lifestyle (e.g. reduced alcohol or sugar intake, increase, or decrease in caffeine) or the use of complementary treatments to aid relaxation. Some individuals preferred not to take medication at all and instead tried to identify and avoid causal triggers.

“I would not take it at the first sign of a migraine I would take it if it were really bad. I would do other things if I could...” (P11).

Individuals sought advice about managing their migraines from a variety of sources including general practitioners (GPs), Pharmacists, Hospital Consultants, as well as other people who experience migraine. Advice-seeking behaviour tended to take place early in their migraine experience and diminished over time depending on the outcome and confidence in self-management.

“I would just go to the pharmacist and ask what the best treatment is...I just do not bother going to the GP about it now, I just try and self-manage” (P1).

Where healthcare providers had not been able to offer effective advice about migraine treatments, individuals made lifestyle changes they believed would help avoid causal triggers.

“...I do too much, so then I try and manage that by doing less. So, lack of sleep, so I try and manage that. Dehydration ...so I do try and drink more water” (P11).

Discussion

The aim of this study was to explore individuals' experiences and perceptions of migraines and their treatment using the Common-Sense Model (CSM) of self-regulation [12]. All participants had experienced a migraine within the past 6 months, and the semi-structured interviews produced a rich narrative that provided an insight into the lives of those who experience migraine. Individuals' perceptions and experiences of migraine were successfully mapped onto the three CSM dimensions (i.e. cognitive illness representation, emotional illness representation and coping/self-management behaviours), illustrating the model's suitability as a framework for exploring individual beliefs about migraine.

The use of a theoretical model to underpin the research demonstrates a strength of this qualitative study to explore individuals' beliefs and behaviours. The prevalence of migraines is estimated to have a female: male ratio of 3:1 [3] which indicates that the ratio of participants (9:2) included in this study is not too dissimilar to that of the population of migraine sufferers. The lack of ethnic diversity in the sample was a limitation since all participants were white; however, migraine prevalence is highest in this ethnic group [15]. Participants were recruited through the use of convenience sampling, which could have limited the variation in the sample, for example, the study only recruited two individuals who were under 40 years of age. The use of maximum variation sampling would have perhaps enabled a broader range of migraine experiences to be documented from a more diverse sample of people.

The intention of this study was not to make generalizations about the role of perceptions in the self-management of migraine; however, the findings broadly support previous research in this area. Participants made sense of their migraines by reflecting on their symptom patterns, frequency, and perceived causal triggers. Across interviews, the core symptoms associated with migraine identity were homogenous and consistent with those set out in the guidelines for management of migraine [4]. This suggests that this group of participants were likely to have appropriately self-diagnosed migraine as opposed to another type of headache. These interviews also highlight the range of symptoms attributed to migraine is often more diverse than what is recognized in the diagnostic criteria; within this small study, there were several perceived symptom perceptions which were unique to individuals.

All individuals in this sample reported that they were able to accurately identify and label their symptoms and had a good understanding of their own individual symptom progression. The process of self-diagnosis reported in this study aligns with the prototype model of disease representation [16], which purports that people hold stable representations of common diseases and interpret their own symptoms by prototype matching. The 'prototype-matching process' found in our study is consistent with Von Lengerke's findings [17], since participants showed a high level of prototype distinctiveness at the disease-specific and disease-cluster-specific levels and were able to distinguish between a migraine and a headache due to typical and distinctive symptoms. It is likely that the ability to self-diagnose migraine improves with

experience, with individuals becoming more able to match their symptoms to disease prototypes as they gain more knowledge about the disease. In these interviews, 24 different causal triggers were attributed to a migraine, and individuals often perceived their migraines to be influenced by more than one factor. Gaining a clear understanding of perceived migraine triggers can help support individuals to make appropriate behavioural or environmental adjustments which improve the management of symptoms [18]. However, uncertainty about the underlying cause of the condition is consistent with data from a meta-analysis of perceived triggers in primary headache disorders, which revealed that individuals reported over 400 unique causes [19].

Participants' experience of migraines often impeded function and influenced their ability to engage in day-to-day life, which impacted emotional wellbeing. When describing the emotional response to migraine, individuals reported two distinct aspects, namely, migraine-specific emotions and the emotional representations of the impact of migraine. These findings are supported by Cooke & Becker [20] study, which explored the psychosocial impact of migraine and conceptualized the patient experience as a double emotional burden. Our study, therefore, recognized the complex emotional impact of managing both chronic pain and functional limitations caused by the condition.

The interviews also explored the factors that influenced the self-management of migraine and provided insight into medicine-taking behaviour. Migraine was viewed as an incurable condition that had symptoms that needed to be controlled. Individuals have trialled numerous pharmacological and non-pharmacological treatments to find the most efficacious. However, despite a wide range of treatment options, some individuals felt that they were unable to successfully self-manage their symptoms. Within this study, several barriers were described, which can inform the understanding of adherence to prescribed medication for migraine; these included the cost of the medication and perceived side effects of medication. Adherence rates for migraine prophylaxis are low and range from 21% to 80% [21, 22]. Horne and Weinman's [23] findings that people tended not to adhere to prescribed medication if the perceived concerns or personal 'cost' of the medicine outweigh the perceived necessity; however, the majority of participants interviewed in this study were not taking regular prescribed prophylactic medication to manage migraine symptoms.

More research is needed to understand factors that influence 'adherence' to prescribed migraine medication that is taken 'as required' to alleviate symptoms as well as non-prescribed medications that are self-selected for symptom management.

Conclusions

This is the first study to apply the CSM to qualitative data to investigate the perceptions of migraine and its treatment in this way. These findings provide rich data to support previous research in this area, illustrating the emotional impact of migraine and the range of illness perceptions that could be influencing patient self-management of this acute, cyclical condition. Quantitative data are needed to establish the prevalence of these perceptions and behaviours before any generalizations can be made to the wider population of migraine sufferers. The next phase of this research is to develop a structured questionnaire, based on these qualitative findings to guide the

development of effective interventions to support migraine management. Based on these preliminary findings, future pharmacy campaigns should be designed in a way that encourages people to get a formal migraine diagnosis from their GP and to inform them about the efficacy of available prescription and non-prescription treatments while addressing concerns they may have about seeking help and self-medicating.

Supplementary Material

Supplementary data are available at *International journal of Pharmacy Practice* online.

Author contributions

C.H.S., R.E., and D.H.J. developed the study concept and design, data collection, analysis, and interpretation. All authors critically revised the manuscript and agree to be accountable to all aspects of this work.

Conflict of interest

The author(s) declare that there are no conflicts of interest.

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Data availability

The author(s) have full access to the study data, and this is ongoing. The data that support the findings of this study are available from the corresponding author upon reasonable request.

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