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Living with Migraine: a Meta-Synthesis of Qualitative Studies

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Abstract

Title: ‘Living with Migraine: a Meta-Synthesis of Qualitative Studies’

Background: Migraine is the third most prevalent disorder and one of the top ten causes of disability worldwide. However, migraine is still underrated in society, and the quality of care for this disease is scant. Qualitative research allows for giving voice to people and understanding the impact of their disease through their experience of it.

Objective: This study aim at synthesizing the state of the art of qualitative studies focussed on people with migraine and how they experience their life and pathology.

Materials and method: MEDLINE via PubMed, EMBASE, CINAHL, PsycINFO and Cochrane Library were consulted up to November 2021 for qualitative studies written in English and published in the last 21 years. Studies to be eligible had to focus on young adults (age > 18 years), with a diagnosis of primary episodic or chronic migraine (ICHD) following the International Classification of Headache. The quality of the studies was analysed using the CASP (Critical Appraisal Skills Programme) tool. The synthesis was done through a thematic analysis. CERQual (Confidence in Evidence from Reviews of Qualitative research) approach was used to assess the confidence in retrieved evidence.

Results: Ten studies were included in the research, counting 259 people with migraine. Our synthesis produced four main themes. 1) ‘Negative impact of migraine symptoms on overall life’ as migraine negatively impacts people’s whole life. 2) ‘Impact of migraine on family, work and social relationship’ as migraine reduces the possibility to focus at work and interact with people. 3) ‘Impact of migraine on emotional health’ as disability due to migraine attacks leads to psychological distress. 4) ‘Coping strategies to deal with migraine’ such as keep on living one’s own life, no matter the symptoms.

Conclusions: This study synthesised the available evidence on the experience of people with migraine and how this disease affects their life. People with migraine are stigmatised at work and during their social life as people struggle with understanding their condition. Thus, it is necessary to

improve awareness among society with educational sessions and to tackle this disease from a social and health-policy point of view, understanding which areas of migraine care need to be addressed.

1 Background

Migraine is classified as a primary headache whose aetiology cannot be found in a specific structural alteration, but a combination of genetic and environmental factors [1, 2]. Migraine is the third most prevalent disorder in the world, the second cause of disability worldwide and 1,3% of years of healthy life lost due to disability [3]. It distresses females more than males in a ratio 3:1, and usually starts in puberty [1] Migraine is the second cause of short-term absence for non-manual workers [a]. Finally, people with migraine experience a broad array of psychological burdens due to their disease [4, 5].

The management of migraine is daunting as there is no defined therapy for this pathology, and the treatment is symptoms-related. People with migraine must learn how to coexist and cope with their disease. Previous studies confirmed that a multimodal approach for migraine is the best treatment. It consists in providing pharmacological interventions as first-line treatment together with non-pharmacological treatments (e.g., muscular and relaxing techniques) [6, 7, 8]. These treatments aim at reducing migraine frequency, duration and intensity [6, 7, 8]. Nevertheless, adherence to guidelines for the attack treatment of migraine is poor [9, 10]. Moreover, migraine is still underrated in society. This underestimation of migraine disability is probably a result of a lack of education and knowledge of this disease among the general population and healthcare professionals [3].

Considering the high impact of this disease and how underrated migraine is, qualitative studies are needed to understand and give voice to people with migraine. In general, qualitative methods allow for gaining relevant information about individuals' personal life experience. They allow for understanding people with different diseases, helping them in their therapeutic process, and improving their clinical management [11]. In migraine, a review published in Headache in 2002 stated that "few studies have been conducted on the patients' perspective on headache" [12]. From that moment, different qualitative meta-synthesis have been produced. Minen et al. conducted a meta-synthesis of qualitative studies in 2017 on migraine management and patients' approach to treatments and physicians [13]. Nichols et al. analysed qualitative studies about the lived experience of chronic headaches, including chronic migraine [14]. However, given that migraine symptoms may overlap tension-type ones, they suggest further exploration [14]. Therefore, we are still missing a meta-synthesis of qualitative studies focussing on people's perception of migraine and their implications on health-related quality of life. Hence, this is the aim of this study.

2 Methods and materials

Meta-synthesis of qualitative studies focusses on patients' perception of a phenomenon and offers different interpretations that help the development of health care settings [15, 16]. For this reason, the meta-synthesis approach suits the aim of this study, whose research question is: "How do people with migraine experience and manage their life?"

The reporting of this meta-synthesis follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA) 2020 [17].

2.1 Eligibility criteria

2.1.1 Types of study

We included qualitative studies written in English and published in the last 21 years (2000-2021) that adopted different approaches (e.g., phenomenological analysis and grounded theory) and data collection methods (e.g., interviews and focus groups). Instead, we excluded studies in languages other than English that adopted quantitative designs such as systematic reviews, case reports, case series and randomised-controlled trials (RCTs).

2.1.2 Types of participants

We considered eligible all the studies that included young adults (age > 18 years) with a diagnosis of primary episodic or chronic migraine following the criteria of the International Classification of Headache (ICHD), with or without typical aura [a]. We did not impose any restrictions on the sex and gender of participants. Therefore, we excluded studies that dealt with children or people with a headache not classified as primary migraine headaches according to ICHD criteria.

2.1.3 Types of evaluation

In this meta-synthesis, the focus is on people's experience of migraine. Thus, we included qualitative studies with people with migraine. Instead, we excluded studies that focussed only on caregivers or physicians.

2.2 Information sources

The research was conducted on MEDLINE via Pubmed, EMBASE, CINAHL, PsycINFO and Cochrane Library. We consulted these databases until November 2021.

2.3 Search strategy

The search strategy adopted is the SPIDER tool used for qualitative evidence synthesis: Sample, Phenomenon of Interest, Design, Evaluation and Research type [15].

The search strings used for all database is reported ad 'Attachment A'. The search strategies were conducted with the help of a librarian from Lund University.

2.4 Selection process

Articles obtained from the research were uploaded to the Rayyan website after duplicate removal. Afterwards, two independent reviewers (AL and LF) selected the studies applying the inclusion and exclusion criteria to titles and abstracts. In case of disagreement, a third author was consulted (SB). Then full texts were read, and the final selection was decided through discussion by two authors. In addition to the inclusion and exclusion criteria, researchers evaluated the sample characteristics to include or not a study. The final purpose of this synthesis is to collect the experiences of a wide range of people with migraine, so if two studies had the same sample and similar settings, only one was included.

2.5 Data collection process

Two authors (AL and IC) independently extracted data from each study following the Cochrane indications [18] and using standardised Excel templates: author (year), title, country, setting, study design, objective, strengths and weaknesses, the total number of participants, sample characteristics, pathology of interest, frequency of migraine, onset/years with migraine and disability rating scale. Then the two authors independently collected themes and subthemes from each study in a second Excel template. Disagreements in the data collection were resolved by either a consensus process or consultation with a third author (SB).

2.6 Methodological quality of the studies and appraisal of certainty

The studies were assessed for critical appraisal with the CASP (Critical Appraisal Skills Programme) tool designed for qualitative studies by two authors independently (AL and IC) [18]. The CerQual (certainty of qualitative evidence) approach was used to assess the certainty of findings as either high, moderate, low or very low: it included the methodological limitations, relevance, coherence and adequacy of data [19, 20]. The methodological limitations of included studies were the result of the assessment made by the CASP tool. The relevance was the extent to which the setting or the inclusion criteria from the primary studies supporting a review finding applied to the context specified in the review question [19]. The coherence assessed data consistency within and across all studies [19]. The adequacy of data was an overall determination of the degree of richness and quantity of data supporting a review finding [19].

2.7 Data synthesis

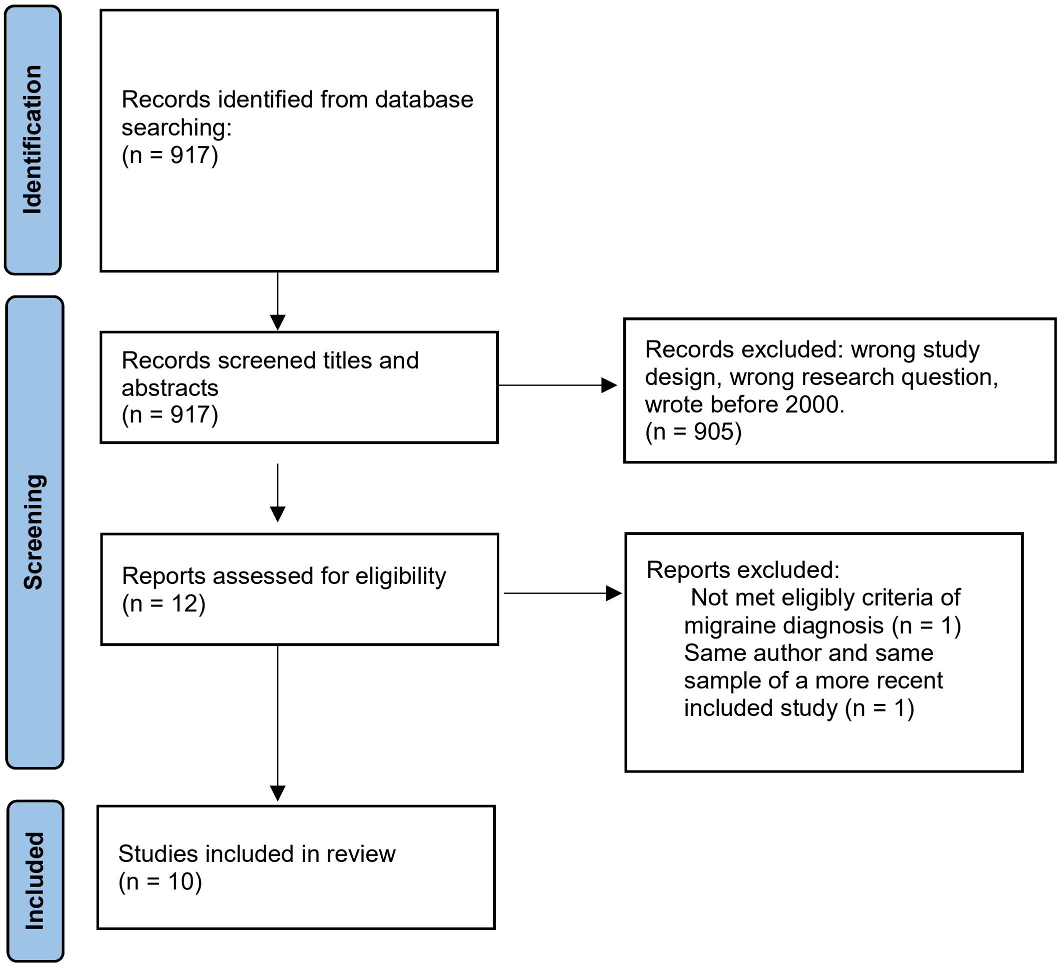
A Thematic Analysis approach was used to synthesise the data [20]. It is a flexible method that identifies main or recurring themes from the included studies, summarising them under thematic headings. In our case, two authors (AL and IC) independently grouped similar themes and subthemes of research findings based on content and then created new themes that synthesised the meaning of the single study ones. The final themes were decided by a consensus process or consultation with a third author (SB).

3 Results

3.1 Study selection

The research conducted on databases yielded 917 articles after the removal of duplicates. After the first screening selection of titles and abstracts, we excluded 905 studies. We read the full text of the remaining 12 articles. We excluded two studies as one did not declare a diagnosis of migraine following ICHD criteria [21] and the other study [22], presented the same sample (perimenopausal women) of a more recent study written by the same author included in this synthesis. Therefore, the final synthesis included ten articles. (Figure 1; PRISMA flow diagram [17])

Figure 1. PRISMA 2020 flow diagram.



3.2 Study characteristics

The ten studies included in the research counted 262 participants with a diagnosis of migraine headache (either episodic or chronic) according to ICHD criteria. Table 1 includes all study characteristics and the different themes and subthemes extracted by the authors of the articles.

Table 1. Summary of findings.

Author (year) and Title	Objective and Qualitative Study Design	Sample and Sampling Strategy	Data collection and Analysis	Themes and Subthemes	Strengths and Limitations reported by authors
Paige M. Estave et al. (2021), ‘Learning the full impact of migraine through patient voices: A qualitative study’ [23]	**Objective**: To characterise better the ways migraine affects multiple domains in the life of adults with migraine **Design**: Semi-structured qualitative interviews based on grounded theory	**Sample**: 81 participants. Average 46 years old in the pilot study; 45 years old in the larger study. 90% of the sample are Caucasian women, privately insured, married, completed college or higher education and self-employed full time. ICHD diagnosis of migraine: • Average frequency migraine days per month: in the pilot study 4,2; in the larger study 7,45, • Years with migraine average: 26 in the pilot study and the larger study, • MIDAS - 1 months: 12,5 for pilot study and 13,7/10,0 for larger study (moderate disability),	**Data collection**: 81 semi-structured qualitative interviews based on grounded theory, open-ended questions, audio recorded and transcribed verbatim by a blinded team member. The interviews from the larger study lasted on average 47 min (SD 13.9). **Analysis**: Transcripts were first summarised into a framework matrix, then uploaded to Dedoose software and the codebook was applied to interviews by six coders. Researchers used a constructive grounded theory approach to identify themes and subthemes. Magnitude coding was applied to establish code frequency.	Six **main themes** and **subthemes**: 1. Global negative impact on overall life: (a) controls life; (b) makes life difficult; (c) causes disability during attacks; (d) lack of control over migraine attacks; (e) attempts to push through despite migraine. 2. Migraine impact on emotional health: (a) isolation; (b) anxiety; (c) frustration/anger; (d) guilt; (e) mood changes/irritability; (f) depression/hopelessness. 3. Migraine impact on cognitive function: (a) concentration difficulties, (b) communication challenges. 4. Migraine impact on specific domains of life with resulting reactions: (a) work/career: guilt, change of job status, presenteeism, financial impact, school impact;	**Strengths**: Large sample size; diagnosis criteria ICHD; rigorous qualitative methodology. **Limitations**: No questions directed to specific domains; selection bias because of the participation in a nonpharmacological study, which may decrease generalisability.

		• HIT - 6: 63 for both studies (severe impact). **Sampling strategy**: Participants were recruited from the pilot RCT conducted by the authors in Boston between January and March 2012 and from the larger RCT conducted in Wistom-Salem between August 2016 and October 2018. These RCTs assessed the effect of a mindfulness-based stress reduction (MBSR) protocol in adults with migraine.		(b) family life: frustration, guilt, disrupted time; (c) social life: irritability, altered plans, communication. 5. Fear and avoidance: (a) pain catastrophizing, (b) anticipatory anxiety, (c) avoidance behaviour. 6. Stigma surrounding migraine: (a) externalized stigma, (b) internalized stigma.	
Palacios-Ceña D. et al. (2017), 'Living with chronic migraine: a qualitative study on female patients' perspectives from a specialised headache clinic in Spain' [24]	**Objective:** To explore the views and experiences of a group of Spanish women with chronic migraine **Design**: Qualitative phenomenological study. The authors adopted in-depth unstructured and semi-structured interviews and patients' drawings.	**Sample**: 20 females diagnosed with chronic migraine according to ICHD with or without medication overuse. • Mean age: 38,65 years (SD 13,85). • Five patients completed primary education, six secondary and six higher education. • Active lifestyle (two housewives, the remainder student or	**Data collection:** 20 participants; In-depth interviews unstructured/semi-structured (tape recording and transcribed verbatim) and drawings of what it is like to live with CM. Unstructured interviews 1-10 started with the open question "what is your experience with CM?"; then keywords are used to clarify the content; length from 73 to 135 min.	Five **main themes** represented patients' experience of suffering CM: 1. The shame of suffering from an invisible condition; 2. Treatment: between need, scepticism and fear; 3. Looking for physicians' support and sincerity and fighting misconceptions; 4. Limiting the impact on daily life through self-control;	**Strengths**: This is the first study to focussing on CM as defined by ICHD diagnostic criteria. Use of multi-method study design. **Limitations**: No generalisability to the whole population with CM due to the inclusion of only women that

		worker outside the home). - Frequency of migraine: mean of 24,6 (SD 4,7) headache days per month, 12,85 (SD 6,03) days of moderate to intense pain and use of symptomatic medication on average of 14,1 (SD 8,91) days a month. - Average years with migraine: 20,2 (SD 13,23). Median time with chronic migraine: 2 years. - BDI-II score (Beck Depression Inventory, second edition) : five patients had mild depression and three had moderate depression. - STAI scores (State-Trait Anxiety Inventory): 14 patients with some degree of anxiety moderate to severe.) **Sample strategy**: Patients were recruited at their	Semi-structured interviews 11-20 based on a question guide design for the specific topic of interest, length from 70 to 139 min. **Analysis**: Thematic analysis, thematic code groups. Two researchers analysed interviews separately and then a meeting was held to combine results and identify final themes.	5. Family and work: between understanding and disbelief.	attended a specialised headache clinic for the first time. The setting of three interviews (coffee shop) could have limited confidentiality.

		first visit to the headache clinic at the Hospital Clìnico San Carlos (Madrid) neurology department between June and December 2016. Sampling continued until redundant information from data analysis was achieved.			
Rutberg S. et al. (2012), 'Migraine – more than a headache: women's experiences of living with migraine' [25]	**Objective**: To explore the meaning of living with migraine **Design**: Hermeneutic phenomenological method, in-depth interviews and drawing.	**Sample**: Ten women aged between 37 and 69 years old. Four women worked full-time, four part-time and two had retired. Eight lived with their husband. Two maintained separate homes from their partners. Four had children living at home and five had adult children. Migraine diagnosed: • One-two attack(s) per year for two women, one-four attacks per month for six women and 10-20 attacks per month for two women. • Eight women migraine started in their late teens or their early twenties. Two women migraine	**Data collection**: Interviews (tape-recorded and verbatim transcribed) started with "Please tell me about your experience of living with migraine"; the interviews finished when no other information could be given. Then participants were asked to draw a picture of what it is like to live with migraine and explain it. **Analysis**: Interrelated phases like seeking meaning, theme analysis, interpretation with reflection.	Three **main themes** and six **sub-themes**: 1. Being besieged by an attack: (a) being temporarily incapacitated, (b) feeling involuntarily isolated from life. 2. Struggling in a life characterized by uncertainty: (a) being in a state of constant readiness; (b) worrying about the use of medication. 3. Living with an invisible disorder: (a) living with the fear of not being believed; (b) struggling to avoid being doubted.	**Strengths**: Multi-method study design. **Weaknesses**: Sample with only women members from the Swedish Migraine Association.

		started in menopause. - Women subjectively estimated migraine impact on their life in three grades: zero slight, four medium and six severe. **Sample strategy**: Letters describing the purpose of the study were sent to all 24 members of Swedish Migraine Association. Participants were contacted by phone, and they all gave written informed consent.			
Ramsey A. R. et al. (2012), 'Living with migraine headache: a phenomenological study of women's experiences' [26]	**Objective**: Understand the meaning of living with a migraine headache to help nurses in their practice. **Design**: Hermeneutic Phenomenological inquiry and story theory with interviews.	**Sample**: Eight women with migraine diagnosis: the average age of migraine onset was 20,5 years. Mean age: 35,9 years. Health insurance coverage: 100%. Access to primary or speciality care 100%. Holding a college degree: 87,5%. Previously pregnant: 50%. Full or part-time employment: 85%. In a committed relationship: 37,5%.	**Data collection**: Eight interviews, audio recorded after informed consent and transcribed verbatim, started with "What is it like to live with migraine headache?" Each conversation lasted 45 min – 1 h. **Analysis**: The stories were transcribed, then a reconstructed story for each participant was written in the participant's	Seven interrelated **themes**: 1. Recalling the significant experience that reshaped life; 2. Experiencing self as vulnerable, with unmet expectations, unfulfilled relationship, and regrets; 3. Being overcome by unrelenting, torturous pain magnified by intrusion from the outside world; 4. Pushing through to hold self together to do what	**Strengths**: Two nurse educators guided the researchers; the findings were confirmed through member checks; external checks and a well-development audit trail. **Limitations**: Authors not explained the limitations of the study.

		Sample strategy: E-mails to every woman who held an account at a mid-Atlantic university. More than 100 women wanted to participate, but the researcher contacted the first 12 who supplied a phone number. The authors decided that redundancy was evident in the eight participant story.	words, and then it was analysed for core qualities descriptors: when headache first experience, view of self, immediate headache experience, getting through the headache and moving through the day. Core qualities were abstracted to interpret themes.	needs to be done despite tortuous pain; 5. Surrendering to the compelling call to focus on self in order to relieve the torturous pain; 6. Making the most of pain-free time to get on with life and navigate the aftermath of the headache experience; 7. Being on guard against an unpredictable attack and yet hopeful that it is possible to outsmart the next attack.	
Peters M. et al. (2005), 'The patients' perceptions of migraine and chronic daily headache: a qualitative study' [27]	**Objective**: To shed some light on patients' perceptions and their experiences of headache. **Design**: Grounded theory methodology. Semi-structured interviews.	**Sample**: 13 adults (nine female and four male) with migraine according to HIS criteria. Five participants also had CDH (>15 attacks per month) and nine from TTH. MIDAS to assess headache-related disability: four participants minimal; one mild; six moderate (three with migraine and three with CDH); two severe disability (CDH). **Sample strategy**: Participants were recruited in Surrey (UK)	**Data collection**: 14 semi-structured, individual, tape-recorded and transcribed verbatim interviews. The interview guide was developed to include previously raised issue and emerging concepts. The first interview was a pilot and was not included in the study. Interviews lasted in a range of 50-90 min. Interviews finished with data saturation. **Analysis**: Interviews were analysed on QSR NUD*IST5 (qualitative	Three **main themes** and **subthemes**: 1. Headaches: (a) pain and other symptoms; (b) differentiating between different types of headache; (c) perceptions of headaches as barriers and facilitators to care. 2. Headache impact. 3. Headache as a health issue.	**Strengths**: Sample formed by dissimilar participants. **Limitations**: Small sample size due to the research design limited the generalisability.

		by personal contact, posters in two local supermarkets and letters to 20 members of the Migraine Action Association.	software package). All authors and an independent researcher were involved in the analysis. A coding guide was used to standardize coding. The analysis involved three stages: the first five interviews were summarised; coded sentence by sentence; the codes were grouped into a hierarchical taxonomy. The remaining eight interviews were used to verifiy the coding scheme.		
Scaratti C. et al. (2018), 'A qualitative study on patients with chronic migraine with medication overuse headache: comparing frequent and non-frequent relapsers' [28]	**Objective**: To explore the psychological and social features and to observe eventual differences between FRs (frequent relapsers) and NFRs (non-frequent relapsers) by considering patients' subjective experience with relapse into CM with MOH. **Design**: Narrative approach, thematic analysis through in-person interviews.	**Sample**: 16 participants, 13 were females, mean age was 53 years old. Seven were classified as FRs and nine as NFRs. Eight participants had a bachelor's degree or higher, five had high school and three had secondary school. Most were married and were a worker. Patients had both psychiatric (depression or anxiety) and physical comorbidity. All participants had a migraine diagnosis (ICHD criteria):	**Data collection**: Audio-recorded interviews, conducted in person: four with FRs and six with NFRs. Recruitment until saturation of themes: the point at which no new themes emerged for three consecutive interviews. At the end of the interview, a brief sociodemographic form was demanded. **Analysis**: Thematic analysis in 3 steps: coding categories extracted from the data; use of the software QRS NVivo 11.0 to analyse the possible	**Four themes** commonly reported by both FR and NFR: 1. Disclosing or concealing headache and the dilemma of isolation. 2. Medication addiction. 3. Anxiety. 4. Use of non-pharmacological therapies. Peculiar **topics** by content: 1. Causal attribution. 2. Future expectations at the time point withdrawal. 3. High performance functioning. 4. Coping strategies. Peculiar **topics** by frequency:	**Strengths**: Authors used a narrative approach "data-driven": data were approached with no specific and previously determined questions. **Limitations**: No consensus as to the precise definition of FR. The recruitment of patients in both the ward and the day-hospital service. The low applicability is due

		- Frequency average 21-22 days of migraine per month. - Years with migraine: FR 18 years; NFR 13 years. **Sample strategy**: Participants were consecutively recruited during structured withdrawal treatments at the Headaches Centre of the Neurological Institute C. Besta in Milan between November 2015 and June 2016. Inclusion criteria: >18 years old, diagnosis of CM and MOH.	connection between contents and coded text and analysis of the qualitative data collected through diagrams. Qualitative aspects were reported for FR and NFR.	1. Awareness of the problem. 2. Symptoms of depression.	to a limited number of participants and the cultural context.
Cottrell C. K. et al. (2002), 'Perceptions and needs of patients with migraine: a focus group study' [29]	**Objective**: To understand: the areas that people with migraines consider most problematic in living with headaches; the types of physician assistance they believe would be most helpful in managing this disorder. **Design**: Focus groups.	**Sample**: 24 white females, aged 25 to 49 years. Participants had a diagnosis of migraine (IHS criteria): - Frequency: two third had one to three migraines per months, each one lasting one to two days; - Two patients also had occasional TTH; - 60% had consulted only the primary care	**Data collection**: A moderator and an assistant using an interview guide conducted focus groups. Eight questions. Approximately 2 hours of discussion. **Analysis**: All sessions were audiotaped and transcribed. Two authors read independently and arranged comments into categories and themes. Disagreements were	**Six primary categories**: 1. Effect on social functioning. 2. Effect on family functioning. 3. Effect on work. 4. Effect on relationships. 5. Issues related to physician care. 6. Problems with insurance and drug companies.	**Strengths**: Authors not explained the strengths of the study. **Limitations**: Small sample size; potential recall bias in remembering interactions with physicians; the focus groups format does not provide information on the prevalence of those

		setting and 40% consulted a neurologist. - Onset: participants experienced migraine for at least six months. **Sample strategy**: Names of potential participants were obtained from a list of people recruited for a separate headache study conducted by two of the authors; telephone screening.	resolved by mutual agreement.		opinions in the population.
Moloney M. F. et al. (2006), 'The experiences of midlife women with migraines' [30]	**Objective**: To describe the experience of midlife perimenopausal women who had migraines. **Design**: Data were collected in two consecutive multi-method studies: first used qualitative interviews, focus group, paper-and-pencil questionnaire (HHQ, Migraine-Specific QoL, SF-36) and six-month daily diaries. The second study was internet-based with both in-	**Sample:** 53 perimenopausal women. Age between 40 and 55 years. Forty-four White, eight African American and one English Indian. Education ranged from high school to graduate school. **Sample strategy**: Ten participants in study one were recruited from a health maintenance organization. Forty-three in study two were recruited from a university setting, the local community and the	**Data collection:** First the authors conducted open-ended interviews, audiotaped for 30 to 60 minutes, in a private place or by phone. Then the participant attended online discussion boards that lasted three to five weeks. Participants also completed questionnaires. Qualitative data were collected until saturation occurred. **Analysis**: Audiotapes were transcribed verbatim and discussion-board data were put into word-	**Three major patterns and themes:** 1. Shifting headache patterns: (a) headaches patterns; (b) looking for an answer. 2. Predicting, preventing, and controlling headaches: (a) is this a migraine or something else?; (b) identifying triggers; (c) course of headache: the lurking migraine; (d) medications; (e) I might try…: self-care interventions. 3. Keeping on the move: (a) working through	**Strengths:** Multi-method studies. **Limitations:** Authors not explained the limitations of the study.

	person and phone interviews, similar quantitative questionnaires and virtual focus groups (online discussion boards). The interpretative hermeneutic approach was used for analysis.	internet. Screening criteria to provide the migraine diagnosis (IHS criteria).	processing software. All these transcripts were transferred to a qualitative software analysis package. An interpretative hermeneutic approach was used to create themes.	headache; (b) desperation; (c) keeping my arsenal of medicine; (d) having a dirty secret.	
Belam J. et al. (2005), ‘A qualitative study of migraine involving patient researchers’ [31]	**Objective:** To develop a research partnership between people with migraine and healthcare professionals, to identify and raise awareness of what it is to have migraines from patients' perspectives to improve management of migraine and to inform the development of a local primary care trust-based headache intermediate care clinic. **Design:** Qualitative interviews, grounded theory.	**Sample:** Eight participants, six females and two males. Average 47,6 years old. HIT: average 70,5 (all results were over 56, which means substantial impact). **Sample strategy:** Patient researchers were recruited from a local intermediate care headache clinic, advertised through the local press, word of mouth and an organisation for people with migraine. Study participants were recruited from a local headache clinic.	**Data collection:** Patients researcher developed an initial question framework and then modified it into a focused conversation. Interviews were taped, but not transcribed. **Analysis:** Authors adopted a consensual interpretative approach. They grouped key statements into categories and defined them into themes.	**Four main themes:** 1. Impact on life (everyone is different): (a) physical and psychological impact; (b) impact on family and social life; (c) impact on career. 2. Making sense of the problem. 3. Putting up with it. 4. Doing something about it: (a) self-help; (b) professional help.	**Strengths:** Involving patients in research as researchers and contributors. **Limitations:** Small sample size due to study design. Superficial analysis of data: interviews were not transcribed and patients researchers analysed the tape.

Ruiz De Velasco I. et al. (2003), ‘Quality of life in migraine patients: a qualitative study’ [32]	**Objective:** To identify those areas of the quality of life of people with migraine most affected by their disease and the impact on different aspects of daily life. **Design:** Six focus groups and nine personal interviews.	**Sample:** Forty-one participants, 29 migraine suffers. • The first, second and third groups were made of participants with migraine: treated with prophylaxis; an average of five crises per month with moderate or severe intensity; an average of 35,7 years old. • The fourth group consisted of participants with migraine: self-medicated; average 48,5 years old; three migraines per month. • The fifth group included healthcare professionals. • The sixth group included relatives of patients. **Sample strategy:** Participants were patients treated in the Department of Neurology of Hospital de Galdakao, Spain.	**Data collection:** Two psychologists led the focus groups. Group sessions lasted 90 min and interviews 30 min. The chairperson used a script for each group with the quality of life aspects liable to exploration. **Analysis:** Sessions were audiotaped. The authors summarised the sessions and organised data into codes and themes. The method used for the analysis was described by Krueger: the researcher offers brief descriptions based on direct data followed by an illustrative example.	**Three main themes:** 1. Symptomatic aspects. 2. Social aspects: (a) work and studies; (b) family relationships; (c) social relationships. 3. Emotional aspects.	**Strengths:** Authors focused for the first time on the perspective of self-medicated patients, family relatives and healthcare professionals. The authors established a script for each group prior to the meeting and used personal interviews to avoid a low level of control over the group. **Limitations:** Low level of control that researchers had over the group intrinsic to qualitative methodology.

3.3 Methodological quality of the studies

The overall evaluations of CASP are collected in Table 2. The single answers with respective explanations for all the studies are reported in Table 3.

Table 2. Evaluations of Methodological Quality of the Studies – CASP Checklist.

Question	Yes (n of studies)	Can't tell (n of studies)	No (n of studies)
1. Was there a clear statement of the aims of the research?	10	0	0
2. Is a qualitative methodology appropriate?	10	0	0
3. Was the research design appropriate to address the aims of the research?	6	4	0
4. Was the recruitment strategy appropriate to the aims of the research?	8	1	1
5. Was the data collected in a way that addressed the research issue?	7	3	0
6. Has the relationship between researchers and participants been adequately considered?	5	5	0
7. Have ethical issues been taken into consideration?	4	6	0
8. Was the data analysis sufficiently rigorous?	10	0	0
9. Is there a clear statement of findings?	10	0	0
10. How valuable is the research?	10	0	0

Table 3. Answers explanations of CASP

Author (year)	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researchers and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Paige M. Estave et al. (2021) [23]	Yes	Yes	Can't tell (it does not explain why they use grounded theory, even if the results seem coherent with the approach)	Can't tell (participants take part in two RCTs and the recruitment strategy is explained in another paper)	Can't tell (it does not explain why they use grounded theory, even if the results seem coherent with the approach)	Yes	Yes	Yes	Yes	Authors specify in the paragraph 'strengths and limitations' the contribution of their study to the existing knowledge and its limitations, such as selection bias and the difficulty of transferring the findings to other populations.

Palacios-Ceña D. et al. (2017) [24]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The authors discussed the strengths and limitations of the study in the paragraph ‘Discussion’. A limitation is the low generalisability due to the women sample. The authors discuss the contributions to existing knowledge explaining that their study is the first to treat CM and compare their findings with ones in current literature.

Rutberg S. et al. (2012) [25]	Yes	Yes	Yes	Yes	Yes	Can't tell (because the considerations explained in the paragraph '*Justification of the study*' are not enough to understand the relationship between researchers and participants)	Yes	Yes	Yes	The authors declare the strengths and limitations of the study in the paragraph 'Methodological considerations'. A limitation is the sample of only women that do not allow for generalising the data to other genders. The authors compare their findings to the current literature in the paragraph 'Discussion'.
Ramsey A.R. et al. (2012) [26]	Yes	Yes	Yes	No (Because the paragraph '*Data collection*' did not explain why they contacted only the first 12 volunteers, which does not justify	Yes	Yes	Can't tell (There is no code or date of approval).	Yes	Yes	The authors discuss the generalisability of their findings and the implications of practice in the paragraph 'Implications for holistic nursing practice'.

				their relevance in responding to the research question).						
Peters M. et al. (2005) [27]	Yes	Yes	Can't tell (it is explained in another paper and the authors do not explain why they use this research design to answer the research question)	Yes	Yes	Can't tell (problem on reporting)	Can't tell (Ethical approval was obtained from the University of Surrey Ethics Committee, but there is no code)	Yes	Yes	In the paragraph 'Discussion' is presented the information this study adds to current literature and which are the further step to investigate. The author discuss the limitations to the generalisability of findings due to the small sample size and the nature of the qualitative analysis.

Scaratti C. et al. (2018) [28]	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell (the ethical committee of the Institute approved the study, but there is neither a code nor the date of approval)	Yes	Yes	In the paragraph ‘Discussion’ the authors explained the value of their approach that was ‘data-driven’ and underlined the limitations such as the not precise definition of FR and the low applicability due to the limited number of participants. The authors explain in the paragraph ‘Conclusion’ the implications for the clinical practice such as considering some relevant psychological aspects of patients.

Cottrel C. K. et al. (2002) [29]	Yes	Yes	Can't tell (the authors do not explain why they use this research design to answer the research question).	Yes	Can't tell (it is not specified why they chose the focus group).	Can't tell (the relationship between researchers and participants is not reported and explained).	Can't tell (there is neither a code nor a date of approval)	Yes	Yes	The authors underline the limitations of the study in the paragraph ‘Discussion’ such as the small sample size and the characteristics of participants that are not generalizable. Authors compare their findings to the current literature and suggest implications for practice lie in need for more general information about migraines and their management.
Moloney M. F. et al. (2006) [30]	Yes	Yes	Can't tell (the authors don’t specify why they use the hermeneutic approach)	Yes	Can't tell (the research issue is not adequately explained)	Can't tell	Can't tell (there is neither a code nor date of approval)	Yes	Yes	The authors discuss their findings compared to current literature in the paragraph ‘Discussion’. A paragraph is dedicate to ‘Implications for

										research, practice and education’.
Belam J. et al. (2005) [31]	Yes		Yes	Yes	Yes	Yes (patients and professionals work together as co-producers of research: paragraph ‘Involving patients in research’)	Yes	Yes	Yes	The authors accepted a lack of rigour because the perspective is more influenced by action research, but underlined the different insights into the investigations that resulted in a practical approach. The authors discussed strengths and weaknesses in the paragraph ‘Strengths and limitations of this study’.

Ruiz de Velasco I. et al. (2003) [32]	Yes	Yes	Yes	Yes	Yes	Can't tell (the relationship between researchers and participants is not adequately reported and explained)	Can't tell (there is neither a code nor date of approval)	Yes	Yes	The authors explain strengths and limitations in the paragraph 'Discussion' and discuss the contribution to existing knowledge: the perspective of self-medicated patients, family relatives and healthcare professionals.

3.4 Results of the synthesis

The synthesis produced four main themes, as shown in Table 4. Every main theme was examined in some subthemes to explain more clearly the various life aspects affected by migraine.

Table 4. Final themes and subthemes.

Themes	Subthemes
1. Negative impact of migraine symptoms on overall life	– Everything is about pain – Disabling symptoms and physical impact – Migraine involves day-to-day life – Inability to carry out activities with pleasure (want to but not be able to)
2. Impact of migraine on family, social and work relationships	– Migraine affects cognitive function (loss of concentration/memory) at work until to change or lose the job – People with migraine are often not understood by their bosses or friends (it is not even considered serious) – Migraine affects the ability to take care of children – Negative impact on the relationship with partner (including sexual relation) – Migraine affects social life (leisure activities, sports, holidays)
3. Impact of migraine on emotional health	– Migraine involves psychological distress (avoidance behaviour, anticipatory anxiety, depression) – Migraine affects intrapersonal emotions (frustration, desperation, irritability, mood changes and hopelessness) – Consequences of social and family aspects on emotional health (isolated, guilty)
4. Coping strategies to deal with migraine	– Self-efficacy as a support to manage migraine – Take advantage of pain-free time – Share experiences – Balance the demands of life

3.4.1 Negative impact of migraine symptoms on overall life

The first theme was presented in most studies (7 out of 10). It included how migraine affected patients' lives through physical symptoms, pain and the consequent inability to function at their best. This was the first theme that came to the light because it explained how migraine negatively affected the lives of people with it and represented the underlying cause of the most negative experiences that emerged in the following subthemes.

Everything is about pain

The participants described the pain as routine [24] and with a range of metaphors that suggested how impactful migraine was for people with it:

> “A freight train coming through”, “A storm entering my head”, “As if my head would explode”. (Ramsey et al. [26]) “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”. (Peters et al. [27])

Disabling symptoms and physical impact

Participants also experienced physical and disabling symptoms such as nausea, vomiting, visual or auditory impairment (aura*).* Aura did not affect all people with migraine, but was considered one of the most disabling symptoms. The noise and the light were described in Ramsey and Ruiz de Velasco’s studies as:

> “Hearing that all day would kill me”, “A stereo that someone just keeps turning the volume up in my head”, “As echoing through my head”, “As fingernails on a chalkboard”. (Ramsey et al. [26])
>
> “And your eyes begin to close because your whole body hurts and you feel pain when there is any kind of noise, light, anything at all” (Ruiz de Velasco et al. [32])

Migraine involves day-to-day life

Because of the disabling symptoms, people with migraine had to live day-to-day, as explained in the studies by Estave [23] and Rutberg [25]:

> “I am losing a day of my life” (Estave et al. [23]), “Attacks make doing day-to-day things a lot more difficult. […] It makes day-to-day living harder” (Estave et al. [23]) “You lose your life for a moment” (Rutberg et al. [25])

Inability to carry out activities with pleasure (want to but not be able to)

The inability due to migraine symptoms also caused a loss of pleasure in daily activities, and it was clearly explained in the study by Estave [23]:

> “I have to stop doing things that I like to do and I can't enjoy things I like to do”, “I never felt real joy because of always having this in the back of my mind” (Estave et al. [23])

3.4.2 Impact of migraine on family, social and work relationships

The second theme focussed on how migraine affects people’s relationships with them. They explained how others considered them and how difficult it was to carry on social life. Participants voiced a problematic concept of not being understood by others, especially in the workplace where there could be consequences on their career up until the loss of their job. This problem sometimes emerged among friends and family whit a certain degree of disbelief because they had to explain an invisible condition. The theme of failing to take care of children was recurrent in the studies by Estave [23], Ramsey [26], Belam [31] and Cottrel [29]. Moreover, in Ruiz de Velasco's study [32], a participant woman expressed the negative impact on sexual relation voicing a common discomfort that was not often mentioned because of modesty.

Migraine affects cognitive function (loss of concentration/memory) at work until to change or lose the job

This theme was recurring among the studies because migraine attacks also involved cognitive functions, and participants underlined the consequences on work:

> "[Migraine] impacts my ability to think clearly and to organize", "I'm a physician, so I sort of grin and bear it", "I've been fired from a job before because of my migraine attacks." (Estave et al. [23])
> "When I've got a migraine I know that I can't give 100%, and that bothers me." (Ramsey et al. [26])
> "I always stay at work. I try to look productive, but I'm only doing half." (Cottrell et al. [29])
> "It affects my career choice." (Belam et al. [31])
> "It's hard to concentrate"; "It affects memory." (Rutberg et al. [25])
> "I lose my coherency. I actually don't know who I am or what anything is and just sounds and colors and brightness then really upset you", "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." (Peters et al. [27])

People with migraine are often not understood by their boss of work or friends (it's not even considered serious)

In most studies, participants voiced the theme of not being understood and its consequences on their life experiences. Here some sentences from study by Estave [23], Palacios-Ceña [24], Cottrel [29], and Ruiz de Velasco [32]:

> "They thought it was a joke because nobody takes it seriously and nobody knows what migraine is", "They've never had it they just think it's a headache and it's not just a headache" (Estave et al. [23])
> "I couldn't prove it and even if they do tests, they can't demonstrate anything.", "My workmate told my bosses that if I had a headache I should take a pill and that it was no excuse not to go to work. Things like that every day.", "I think that like any other pain, those who don't suffer from it don't understand. Ignorance leads to incomprehension. It is a condition that has a bit of a bad reputation." (Palacios-Ceña et al. [24])
> "I think people look like 'yeah, right, everybody has headaches. They're not that bad, just get a grip and keep going" (Cottrell et al. [29])

> "The others don't understand because it is a sharp pain and if you haven't experienced it you can't imagine what it's like" (Ruiz de Velasco et al. [32])

Migraine affects the ability to take care of children

Migraine often made childcare difficult, according to participants, who expressed it this way:

> "Being a mom makes it very challenging after you've worked all day", "I feel like I can't take care of him (18-month-old)" (Estave et al. [23])
>
> "As a mother you are the primary caregiver and it's very difficult to think that there are times when you can't take care of your child. […] I can't take care of my child. I can't even take care of myself at this moment" (Ramsey et al. [26])
>
> "It's a disaster at home […]. 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." (Peters et al. [27])
>
> "I'm not the mom I wanted to be" (Cottrell et al. [29])
>
> "My son is only 11 and he has never known me any different" (Belam et al. [31])

Negative impact on the relationship with partner (including sexual relation)

The consequences of migraine attacks were also reported in the association with the partner, as the participants explained:

> "It affects my husband because it puts more on him when I have one." (Estave et al. [23])
>
> "[…] My husband just pitches in when I get one." (Peters et al. [27])
>
> "It's changed my life even in our sexual relations because since I began to have this pain I haven't felt any kind of sexual arousal." (Ruiz de Velasco et al. [32])

Migraine affects social life (leisure activities, sports, holidays)

Participant's experiences also involved social life, as explained in the paper by Palacios-Ceña [24] and paper by Scaratti [28]:

> "You can't lead a normal life, you can't go out dancing, to dinner, to the cinema. It changes the way you live.", "It limits the time I can spend with my friends and even the desire to do sport." (Palacios-Cena et al. [24])
>
> "Social life is affected a lot…I no longer have any relationship with them (friends)…the others after a while got tired of me." (Scaratti et al. [28])

3.4.3 Impact of migraine on emotional health

The third theme dealt with emotional features that followed migraine and affected participants' lives even from a psychological aspect.

Migraine involves psychological distress (avoidance behaviour, anticipatory anxiety, depression)

Psychological distress was common among participants, who suffered a lot and often presented themselves as overwhelmed by this condition. Depression and anxiety were the most reported feelings such as in Estave's [23] and Scaratti's [28] studies:

> "[Attacks] cause a lot of anxiety because I don't know when I'm going to have one and I'm fearful I'm going to have one when something comes up. And when I have one, I'm fearful it's not going away." "…also the anxiety about it, being anxious about maybe having to leave work or maybe not do thing at home, maybe not cook dinner." (Estave et al. [23])
>
> "It's anxiety…It's feeling bad…having a life that is always affected…you always need to have a painkiller in your bag. […] I can't fully live my life and enjoy the things I do." "I feel a little depressed. […] I can't react anymore, I'm tired of my headache." (Scaratti et al. [28])

Migraine involves intrapersonal emotions (frustration, desperation, irritability, mood changes and hopelessness)

Participants expressed their emotions such as frustration and desperation with a condition that was difficult to explain and face [23, 30, 31, 32]. Emotions such as irritability and mood changes also affected the social relation triggering a vicious circle of discomfort [23, 24].

> "It's frustrating at times because it takes away from family time…You don't feel as well as you want to." "I'm more irritable and don't want to be around a lot of people." (Estave et al. [23])
>
> "Desperation is definitely part of the day" (Moloney et al. [30]); "I feel a sense of failure when I have headache" (Belam et al. [31]); "You are always in a bad mood and besides". (Ruiz de Velasco et al. [32])
>
> "I get in such a bad mood that I can't stand anyone, you're irritable, you do not anyone talk to you, no-one to tell you anything […] you get frustrated and you even feel isolated" (Palacios-Ceña et al. [24])

Consequences of social and family aspects on emotional health (isolated, guilty)

Participants of Estave's study [23] explained that physical and psychological symptoms led to feelings of isolation and guilty about time away from social engagement and family duties:

> "I'm sorry it affects me because it takes me away from my family, my kids … And anytime that I can't spend time with them it hurts me; it makes me feel bad. It makes me [think] that I'm have a problem."

> “My daughters, my husband and everybody … they just stopped including me in everything, so I felt like I was observing them live, but I wasn’t really living.”

Participants of Scaratti’s [28] and Palacios-Ceña studies [24] explained the feeling of isolation:

> "Social life is affected a lot. I am isolated from almost all of the people I know, except from my family of origin and from some friends…but I no longer have any relationship with them…the others after a while got tired of me." (Scaratti et al. [28])
>
> "It cut you off from being with others; it separates you from everyone else" (Palacios-Ceña et al. [24])

3.4.4 Coping strategies to deal with migraine

The last theme underlined the coping strategies that participants shared in the studies. Participants voiced concern about the implications of migraine on every aspect of life and, in most cases, it was hard to take on. However, they shared the strategies they adopted against the disability caused by attacks to cope with migraine.

Self-efficacy as a support to manage migraine

Participants expressed their willingness not to be overwhelmed by pain. Therefore, they lived trying to go through the attack, managing it, as stated in the study by Palacios-Ceña [24]. The women in Ramsey’s study explained the will to keep on doing their activities, no matter the symptoms, to meet their expectations in a social or work context [26]. However, they also showed to be aware about taking care of themselves [26]. Belam et al., in their study, talked about people with migraine’s self-help to cope with attacks and to look for remedies [31]. The participants in Moloney’s study added that it was essential to focus on causes and triggers to increase prediction and control [30].

> “You try not to let it affect you, to control everything, to deal with it, to be conscious of everything that might cause pain.” “I try to tolerate the pain as much as I can.” (Palacios-Ceña et al. [24])
>
> “[…] Caffeine sometime will help, but you just have to go on through it.” (Ramsey et al. [26])

Take advantage of pain-free time

Another strategy voiced by participants was using time devoid of pain to engage in activities like exercise and stress reduction to prevent other attacks and reduce the frequency, as explained by Ramsey [26].

> “The good things are certainly that you don’t have headache, but sometimes during the inactive phase you’re actually getting over another one and so you’re trying to recoup, and sometimes redo things that you have done halfway […]. I try to take those inactive times to really enjoy life.”

Share experiences

Participants in Belam study voiced the need to share experiences, talk to others and explore meaning because they need to understand the condition and place it in the context of their lives [31].

> "It was been very helpful to be able to talk to and listen to other people who suffer from migraine",
> "When you realise that other members of the family have migraine you feel the battle is over – you understand why you get them"

Balance the demands of life

Living with migraine was a constantly evolving process that required constant attention and vigilance. This process included the ability to balance the demands of life, as explained in Rutberg's study [25].

> "You learn to live with it and you do not know what life would be without it, but it is like permanently wearing a backpack, which is though, you must always consider the possibility not being able to do things."

Participants voiced that they lived in a constant state of readiness to avoid triggers and control the attack. They described migraine with this metaphor:

> "It's a though I am forced to live with somebody who always interrupts and decides what I should or should not do" (Rutberg et al. [25])

3.5 Certainty of evidence

As described in the paragraph method, the CerQual (certainty of qualitative evidence) approach was used to assess the certainty of findings (Table 5) [19]. None of the study findings was evaluated to be higher certainty because of weaknesses in relevance and minor methodology limitations of included studies. All the study findings were assessed as moderate confidence, which meant a good level of certainty because of minor concerns regarding coherence and adequacy of data within and across all studies included.

Table 5. Certainty of Evidence (CerQual)

Review Finding	Studies Contributing to the Review Finding	Assessment of Methodological Limitations	Assessment of Relevance	Assessment of Coherence	Assessment of Adequacy of Data	Overall CerQual Assessment of Confidence	Explanation of Judgement
Negative impact of migraine symptoms on overall life	Paige M. Estave et al. [23], Palacios-Ceña D. et al. [24] , Rutberg S. et al. [25] , Ramsey A.R. et al. [26] , Peters M. et al. [27] , Belam J. et al. [31] , Ruiz de Velasco I. et al. [32]	Minor methodological limitations (two studies with no limitations, one with minor limitations on research design, recruitment strategy and data collections, one study with moderate methodological limitations on recruitment strategy and the other studies have minor methodological limitations)	Substantial concerns about relevance (all the studies included only Caucasian people)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (seven studies that offered together moderately rich data overall)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, coherence and adequacy; though substantial concerns about relevance.

Impact of migraine on family, work and social relationships	Paige M. Estave et al. [23], Palacios-Ceña D. et al. [24] , Rutberg S. et al. [25] , Ramsey A.R. et al. [26] , Peters M. et al. [27] , Scaratti C. et al. [28] , Cottrel C. K. et al. [29] , Belam J. et al. [31] , Ruiz de Velasco I. et al. [32]	Minor methodological limitations (two studies with no limitations, one study with concerns on research design and data collection, one study with concerns with research design, recruitment strategy and data collection, one with moderate concern on recruitment strategy and the other studies have minor methodological limitations)	Substantial concerns about relevance (all the studies included only Caucasian people)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (nine studies that offered together moderately rich data overall)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, coherence and adequacy; though substantial concerns about relevance.
Impact of migraine on emotional health	Paige M. Estave et al. [23], Palacios-Ceña D. et al. [24] , Rutberg S. et al. [25] , Ramsey A.R. et al. [26] , Scaratti C. et al. (2018) [28] , Moloney M. F. et al. (2006) [30] , Belam J. et al. [31] , Ruiz de Velasco I. et al. [32]	Minor methodological limitations (two studies with no limitations, one study with concern on research design, recruitment strategy and data collection, one study with minor concern on research design and data	Substantial concerns about relevance (all the studies included only Caucasian people)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (eight studies that offered together moderately rich data overall)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, coherence and adequacy; though substantial concerns about relevance.

		collection, one study with moderate concern on recruitment strategy and the other studies have minor methodological limitations)					
Coping strategies to deal with migraine	Palacios-Ceña D. et al. [24] , Rutberg S. et al. [25] , Ramsey A.R. et al. [26] , Moloney M. F. et al. (2006) [30] , Belam J. et al. [31]	Minor methodological limitations (two studies with no limitations, one study with minor concerns, one with concerns on research design and data collection and one with moderate concerns on recruitment strategy)	Substantial concerns about relevance (all the studies included only Caucasian people)	Minor concerns about coherence (data reasonably consistent within and across all studies)	Minor concerns about adequacy (eight studies that offered together moderately rich data overall)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, coherence and adequacy; though substantial concerns about relevance.

4 Discussion

This meta-synthesis is the first one that focusses exclusively on the life experiences of people with migraine. From our synthesis, four main themes were brought to the forefront: 'Negative impact of migraine symptoms on overall life'; 'Impact of migraine on family, work and social relationships'; 'Impact of migraine on emotional health'; 'Coping strategies to deal with migraine'. These themes are in line with the meta-synthesis of Nichols et al.' on chronic headache [14]. Let us suppose we drew some comparisons with our study. In this case, we could argue that people with chronic headaches, from different genesis, share a similar detrimental experience to the participants of the studies in our review. This shared experience stemmed from a similar sense of suffering, difficulties organising work and household chores, blaming one's own situation and other psychological distress such as anxiety, no matter the genesis of the headache. Our themes can also overlap with the ones retrieved from two qualitative studies on adolescents with migraine, which were excluded from this meta-synthesis as we focussed only on adults. Nevertheless, it is interesting because overwhelming pain and a sense of isolation caused by migraine are present regardless the age. However, the need to share experiences and social support is more evident among adolescents [33, 34].

The first theme 'Negative impact of migraine symptoms on overall life', showed that migraine symptoms are disabling and affect everyday life. This is in line with the current quantitative literature about the quality of life of people with migraine [35, 36, 37]. The quantitative data suggests that people with migraine experience disability during everyday life that increases with headache intensity [37]. The qualitative data from this meta-synthesis delve into the quantitative ones, explaining where the disability has its greatest impact. For example, Estave et al. explained how people with migraine experienced doing things without pleasure or wanting to do something, but their disease hindered this attempt [23].

However, the most significant burden of people with migraine emerges in the work and social fields, as we explain in the second theme 'Impact of migraine on family, work and social relationship'. This theme focussed on how people with migraine perceived their disease to impact different spheres of life, namely, family, work and social relationship. When it comes to the family and work sphere, people with migraine reported these spheres to be hindered by migraine attacks. This is in line with a study by Buse et al. where the authors reported migraine harmed people's careers and the feeling of being 'good parents' in one-third of their population [35]. Thus, quantitative data underlines the prevalence of negative impact on jobs, whereas qualitative data shed some light on where these problems are. In particular, people with migraine reported the loss of cognitive function (concentration and memory) while at work due to their symptoms. This sense of discomfort is further worsened by the lack of understanding from their bosses. When it comes to intimate relationships, Buse et al. underlined the difficulty of people with migraine in establishing and maintaining a relationship, ending up breaking up with their partner because of the recurrence of attacks that affect the ability to do things together [35]. Ruiz de Velasco et al. highlighted that migraine could also impact the sexual sphere because of the pain of migraine attacks and its negative consequences on sexual arousal [32]. Problems in sexual spheres for these people can be underrated by a general sense of embarrassment, stigma and cultural taboo. People during focus groups felt embarrassed to talk about this topic, while they felt more at ease during individual interviews [32]. Talking about sex is a challenge in healthcare [38]. However, for some people, sexuality is an essential yet complex phenomenon to feel ashamed about. This aspect must be taken into account during the care process for people with migraine, to offer them multidisciplinary support that tackles this disease from different perspectives.

The third theme 'Impact of migraine on emotional health' underlines the effects of migraine on emotional health. In the studies retrieved in our meta-synthesis, people with migraine reported a general sense of guilt. One participant stated, "It's my brain, it's my fault" [23]. This sense of guilt was reported by other participants and it is an overarching theme that was recently pointed out as one of the elements that contribute to the migraine burden [23]. Rutberg and Moloney highlight that participants' guilt might also stem from the stigma of migraine due to the lack of awareness and understanding of this disease in society [25, 30]. As regards the issue of not being understood by others that could lead to isolation, Estave explains that improving knowledge and awareness of migraine in the general public could reduce emotional disorders in people with migraine [23]. These burdensome feelings can be one of the reasons behind the high prevalence of psychological distress among people with migraine. To previous evidence, 23.1% of people with migraine experience psychological distress [39, 40]. The study by Chu et al. emerged that the severity of depression and anxiety are related to migraine frequency and can alter the perception of pain [41]. Generalised anxiety disorders and major depression are the most common psychiatric disorders experienced by people with migraine, and they are both reported by the participants in the qualitative studies of our meta-synthesis [39]. Therefore, it is fundamental to consider also those elements once taking charge of people with migraine as it impacts their life and health outcomes.

The final theme dealt with the 'Coping Strategies to deal with migraine' that people with migraine brought to the forefront to deal with their disease. These strategies included the importance of self-efficacy, taking advantage of pain-free time, sharing experiences and balancing the demands of life. Palacios Ceña et al. underlined that their study participants wanted to go and live through the attacks, managing them [24]. Believing in the ability to produce specific performance attainments in their available capacity is called 'self-efficacy' [40]. High levels of self-efficacy were reported as a key factor in preventing attacks and adaptation to pain [40]. However, as written by Ramsey et al., they can push through the pain also to meet their and others' expectations, levering on external motivation [26]. Nevertheless, the participants were aware of when they needed to take care of themselves through different strategies, from taking medications to going to a cold dark room to eliminate all external stimuli and resting as much as needed [26]. Multimodal treatments should be considered where this and other coping strategies are offered and shared with patients to help them handle their symptoms and increase their level of self-efficacy.

Pain-free time is essential in a contest to reduce triggers and control the attacks: for example, patients should take advantage of pain-free time to maximise the effect of first-line treatments. Ramsey and Moloney explain that some participants affirmed they used the pain-free time to do exercise and stress reduction activities. However, they voice a sense of uncertainty while waiting for the next attack [26, 30]. Thus, it is crucial to inform people with migraine to take advantage of different stress management strategies such as exercise, manual therapy and meditation during the pain-free time to reduce the intensity and frequency of headache.

Several limitations of this study need to be addressed. This meta-synthesis has a sample made mostly of Caucasian people. The participants in our meta-synthesis came mainly from America and Europe. Moreover, most of the participants were women. However, this is in line with the worldwide prevalence of migraine, which is more common in women than men [42]. We included both episodic and chronic headache, which could be limiting. However, the meta-synthesis by Nichols et al. on chronic headache underlined similar themes.

The strengths of this study are the rigorous and sensitive research we performed with the help of a librarian and the fact that we included only participants with migraine diagnosis (ICHD criteria). Moreover, we use the CerQual to assess the certainty of the evidence of our findings.

5 Conclusion

To sum up, this study synthesised the available evidence on the experience of people with migraine and how this disease impacts their life. Several spheres of quality of life are jeopardised, namely, work, social and sexual life and emotional health. Moreover, people with migraine felt to be unseen by the society. The lack of awareness about their condition and empathy by society and healthcare professionals add a further burden to people with migraine. People with migraine are stigmatised at work and during their social life as people struggle with understanding their condition.

There is a need to tackle this disease from a social and health-policy point of view. As for the former, not only do we need to educate people with migraine about their condition, but we also need to do it with those around them. Broad awareness campaigns and educational sessions with relatives could be a solution to make migraine 'visible' to the society. As for the latter, the health-policy makers, the findings of this qualitative review can help them understand which areas of migraine care need to be addressed. A 'one-size-fits-all' solution appears not to be possible due to the complexity of this disease. Tailored and evidence-based care processes need to be promoted. Based on people's symptoms, they need to contact a specialised multi-professional team composed of different healthcare professionals (e.g., neurologists, psychologists and physiotherapists) trained in migraine management. Finally, also research needs to move towards these people. People with migraine should be involved in research. It is vital to adopt specific frameworks for supporting their involvement in research, to understand what matters when it comes to the management of their disease.

6 Key points

- This meta-synthesis sums up qualitative evidence on experiences of people with migraine episodic or chronic following ICHD criteria.
- Four main themes that involve migraine's impact on every aspect of life were found: 'Negative impact of symptoms on overall life', 'Impact on family, work and social relationship', 'Impact on emotional health', 'Coping strategies to deal with migraine'.
- This synthesis pointed out the need for people with migraine to be understood by society and the requirement to develop specific health policies.
- Our suggestions are to introduce broad awareness campaigns with general population and educational sessions with relatives and to promote an evidence-based process with a multi-professional team composed of professional figures such as neurologists, psychologists and physiotherapists.

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Webliography

a) https://ihs-headache.org

Attachment A

Medline via Pubmed: ((("Migraine Disorders"[Mesh] OR "Headache Disorders, Primary"[Mesh] OR "Headache Disorders"[Mesh] OR Migraine OR Migrain* OR Headache OR Head pain) AND ("Surveys and Questionnaires"[Mesh] OR "Interview" [Publication Type] OR "Focus Groups"[Mesh] OR "Observation"[Mesh] OR “Nursing Methodology Research”[Mesh] OR "Hermeneutics"[Mesh] OR "Patient Acuity"[Mesh] OR "Grounded Theory"[Mesh] OR "Narration"[Mesh] Questionnaire OR Survey OR Interview OR Focus group OR Case stud* OR Observ* OR Qualitative research OR Qualitative method OR Hermeneutics OR Phenomenology OR Grounded theory OR narration OR Story-telling OR Storytelling OR Story telling)) AND ("Life Change Events"[Mesh] OR "Attitude"[Mesh] OR "Behavior"[Mesh] OR "Emotions"[Mesh] OR "Quality of Life"[Mesh] OR "Activities of Daily Living"[Mesh] OR "Social Participation"[Mesh] OR "Patient Participation"[Mesh] OR "Knowledge"[Mesh] OR "Health Knowledge, Attitudes, Practice"[Mesh] OR "Metacognition"[Mesh] OR "Perception"[Mesh] OR "Pain Perception"[Mesh] OR "Social Perception"[Mesh] OR "Self Concept"[Mesh] OR "Attitude"[Mesh] OR "Attitude to Health"[Mesh] OR "Emotions"[Mesh] OR "Behavior and Behavior Mechanisms"[Mesh] Experience* OR Opinion* OR Quality of life OR Belie* OR Feel* OR Attitude* OR Participation OR Emotional Involvement OR Self-concept OR Self concept OR Image OR View* OR perspective OR Perception OR Feeling* OR Behavi*)) AND ("Qualitative Research"[Mesh] Qualitative OR Mixed method) → 422 entries 19/10/2021

EMBASE: ('migraine'/exp OR ('headache'/exp AND 'facial pain'/exp) OR 'headache'/exp OR migraine) AND ('questionnaire'/exp OR 'interview'/exp OR 'focus group'/exp OR 'focus group discussion'/exp OR 'focus group interview'/exp OR 'nursing methodology research'/exp OR 'hermeneutics'/exp OR 'observation'/exp OR 'patient acuity'/exp OR 'grounded theory'/exp OR 'phenomenology'/exp OR 'storytelling'/exp OR 'qualitative research'/exp OR 'survey'/exp) AND ('life event'/exp OR 'attitude'/exp OR 'behavior'/exp OR 'emotion'/exp OR 'quality of life'/exp OR 'daily life activity'/exp OR 'social participation'/exp OR 'patient participation'/exp OR 'knowledge'/exp OR 'attitude to health'/exp OR 'metacognition'/exp OR 'perception'/exp OR 'nociception'/exp OR 'self concept'/exp OR 'experience'/exp OR 'belief'/exp OR 'feeling'/exp OR 'participation'/exp OR 'image'/exp OR 'perspective'/exp OR opinion OR (emotional AND involvement)) AND ('qualitative research'/exp OR 'mixed method study'/exp OR 'mixed methods study'/exp OR 'mixed method'/exp

OR 'mixed methods'/exp OR 'mixed methods research'/exp OR 'qualitative'/exp) AND [2000-2021]/py → 272 entries 19/10/2021

CINAHL, Psychinfo and Socindex: (migraine OR headache OR migraine headaches) AND (interview OR survey OR questionnaire OR focus group OR observation OR nursing methodology research OR hermeneutics OR patient acuity OR grounded theory OR narration OR phenomenology OR storytelling) AND ((life change events OR (attitudes and behaviour) OR emotions OR quality of life OR activities of daily living OR participation OR self concept OR health knowledge, attitudes, practice OR perception OR experience OR knowledge OR metacognition)) AND (qualitative OR mixed methods) → 328 entries 19/10/2021

Cochrane Library Central: Search Name: Meta sintesi Migraine 2 75 Entries 19/10/2021

ID	Search	Hits
#1	MeSH descriptor: [Migraine Disorders] explode all trees	2812
#2	MeSH descriptor: [Headache Disorders] explode all trees	3541
#3	migraine	8447
#4	head pain	6109
#5	headache	35324
#6	#1 OR #2 OR #3 OR #4 OR #5	42848
#7	MeSH descriptor: [Surveys and Questionnaires] explode all trees	56906
#8	MeSH descriptor: [Interview] explode all trees	7
#9	interview	24445
#10	MeSH descriptor: [Observation] explode all trees	183
#11	MeSH descriptor: [Nursing Methodology Research] explode all trees	227
#12	MeSH descriptor: [Hermeneutics] explode all trees	2
#13	hermeneutic	31
#14	patient acuity	4192
#15	MeSH descriptor: [Grounded Theory] explode all trees	15
#16	MeSH descriptor: [Narration] explode all trees	212
#17	narration	282
#18	case study	66467
#19	story-telling	64

#20 story telling 101

#21 storytelling 285

#22 phenomenology 208

#23 grounded theory 670

#24 #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 145524

#25 MeSH descriptor: [Life Change Events] explode all trees 439

#26 life change events 12007

#27 MeSH descriptor: [Attitude] explode all trees 39430

#28 attitude 16297

#29 MeSH descriptor: [Behaviorism] explode all trees 2

#30 behavior 93570

#31 MeSH descriptor: [Emotions] explode all trees 18330

#32 emotion 7720

#33 MeSH descriptor: [Quality of Life] explode all trees 26469

#34 "quality of life" 125632

#35 MeSH descriptor: [Activities of Daily Living] explode all trees 9850

#36 "activities of daily living" 12002

#37 MeSH descriptor: [Patient Participation] explode all trees 1458

#38 participation 34853

#39 MeSH descriptor: [Health Knowledge, Attitudes, Practice] explode all trees 6180

#40 MeSH descriptor: [Metacognition] explode all trees 87

#41 metacognition 346

#42 MeSH descriptor: [Perception] explode all trees 18033

#43 perception 27590

#44 MeSH descriptor: [Self Concept] explode all trees 7386

#45 self concept 9640

#46 attitude 16297

#47 MeSH descriptor: [Attitude] explode all trees 39430

#48 experience 58534

#49 belief 3858

#50 believes 2081

#51 perspective 12317

#52 feeling 6576

#53 #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 358714

#54 MeSH descriptor: [Qualitative Research] explode all trees 1197

#55 qualitative 18286

#56 mixed-method 829

#57 mixed method 11997

#58 #54 OR #55 OR #56 OR #57 28851

#59 #6 AND #24 AND #53 AND #58 1147

→ da 2000 a 2021, only trials