A meta synthesis of the experience of chronic temporomandibular disorder patients within the healthcare services.

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Abstract

Objectives: the aim of this review was to systematically review the qualitative evidence related to the experience of patients with temporomandibular disorder (TMD) and explore their journey within the healthcare services. **Materials and methods:** a systematic search of the following data bases was conducted: Medline, Embase, PsycINFO, Web of Science, CINAHL Complete and the Cochrane database. Thematic synthesis was used to analyse and sythesise the data from qualitative studies which explored the journey of TMD patients within the healthcare services. The CASP tool was used to critically appraise the quality of the included studies. **Results**: the search strategies yielded 4563 articles across all databases, of which,18 articles were eventually included. Six themes were derived: care seeking attitudes, expectations and healthcare experience, the patient-clinician interaction, diagnosis as a stepping-stone for improvement, management and social support. **Conclusion:** the journey within the healthcare services may play a valuable role in the ability to cope with chronic TMD. Receiving a diagnosis, being listened to, and believed are among the important elements which make for a positive clinical experience.

Key words: temporomandibular disorders, healthcare services, patient experience, qualitative evidence synthesis, chronic pain.

1. Introduction

Temporomandibular disorder (TMD) is a collective term embracing a number of clinical problems that involve the masticatory musculature, the temporomandibular joint and associated structures, or both [1]. It is a common condition that may affect up to a third of the general population [2]. The symptoms range from pain in and around the TMJ and surrounding muscles, to functional changes such as limitation of mouth opening, and deviation of mandibular movements. Patients with TMD could also frequently present with stress and anxiety as a result of the chronic nature of their pain. Indeed, chronic musculoskeletal pain is a prominent public-health problem and a leading cause of sick leave [3, 4]. Patients with chronic pain conditions also reportedly use healthcare services more frequently than other patient groups [5] [6]. It has been suggested that although clinicians may adhere to guidelines in their management of pain, they may not always consider patients views on management strategies[7]. This may result in unmet patients' expectations and promotes excessive use of health services to help cope with the pain. Breckons et al additionally suggest that the current healthcare pathways for chronic orofacial pain patients in the UK do not appear to meet the patients' needs [8], resulting in multiple unnecessary consultations and increased healthcare resource utilisation [9].

Patient-centred care (PCC) is a way to empower patients and expand their role in healthcare. The aim of this approach is to provide patients with reassurance, comfort, support, legitimacy and confidence [10]. It therefore assumes that they are capable of deciding what happens to their own bodies, and the role of clinicians is to support them with advice and deliver healthcare in line with their needs [11]. Government bodies and policy makers around the world are increasingly recognising the importance of PCC along with the merits of a pleasant hospital experience for the patients [12-14]. In the UK, the National Health Service (NHS) have identified hospital experience as a pillar of patient care alongside clinical effectiveness and safety. Additionally, the NHS National Quality Board (NQB) released a framework in 2011 that details the elements which are critical to the patients' experiences of NHS services. Some of the elements are respect for patient-centred values, emotional support, coordination of care and providing enough information [15].

Several qualitative studies have provided insight into the experiences of patients with TMD with the healthcare services. Qualitative evidence synthesis, however, offers greater understanding by bringing together the available research on this topic. It helps inform our practice and provide care that meets the patients' needs as recounted by them [16]. To our knowledge, there is no qualitative review that focused on the experiences of TMD patients within the healthcare services. Thus, the aim of this study was to systematically review and synthesise the available qualitative evidence related to the experience of TMD patients within healthcare, to highlight the important aspects of care to them and explore the difficulties they encounter.

2. Materials and methods

The key words for the search were based on the SPICE acronym. This framework was first proposed by Booth and is comparable to the PICO acronym commonly used in quantitative systematic reviews [17]. The concepts of the framework were as follows; **Setting**: healthcare, **Perspective**: patients, **Phenomenon of Interes**t: temporomandibular disorders, **Comparison:** none, **Evaluation**: patient experience/satisfaction.

The search strategy aimed to locate all available articles and involved three steps. Firstly, an initial search was run using Medline and Embase to identify MeSH terms and key words describing our search. The following MeSH terms and keywords were used:

(Temporomandibular Joint Disorders or Temporomandibular Joint Dysfunction Syndrome or Facial Pain or fac* myalgia or masticat* muscle pain*) AND (Personal Satisfaction or Attitude or experience* or satisfaction* or healthcare service* or health care service* or perspective* or concern* or opinion*) AND (Qualitative research or Interview or Focus groups or qualitative stud* discussion* or audio recording*)

Secondly, the published articles were identified by running the search strategy in the following databases in May 2022: Medline, Embase, PsycINFO, Web of Science, CINAHL Complete and the Cochrane database. Finally, hand searching of the references lists of the included articles was performed for additional studies that may have been missed form the previous search. The full search strategy can be found in the supplementary material.

2.1. Study selection

The studies eligible for inclusion were qualitative studies that reported on aspects of TMD patients' experience within the healthcare services. Mixed method studies were included if they contained a qualitative component that was separate from the quantitative component. Studies with a sample of patients with a mix of chronic orofacial pain (COFP) conditions were also included if they contained a sample of TMD patients. The data and quotes attributed to TMD patients were included, in addition to the findings which were not attached to a particular pain condition. This approach was used as the findings in such studies applied to the various COFP conditions under investigation, including TMD. The findings and quotes which were assigned to another pain condition, such as Persistent Idiopathic Facial Pain or Trigeminal Neuralgia were excluded from the analysis. This method was adopted as focusing solely on papers with a pure sample of TMD might result in missing important findings in studies with a mixed cohort of orofacial pain conditions. The eligible studies also reported on patients over the age of 16 (16 was used as it is the age when children transition into the adult healthcare services in the UK) and were written in the English language. Studies were excluded if they focused on the experiences with a specific treatment or intervention, if they did not contain data regarding the experience within healthcare or if the full text was unavailable.

2.2. Critical appraisal of the studies

The review process was undertaken in two stages by two reviewers (DT and RNR). First, the title and abstract of the search results were screened against the inclusion and exclusion criteria. Those which met the inclusion criteria moved through to the second stage of reviewing the full article. The final decision to include the articles in the review was made after discussions among the team.

The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist was used to appraise the methodological quality of all papers. This tool was chosen because it is the most commonly used tool in qualitative evidence syntheses in Cochrane and World Health Organisation (WHO) guideline processes [18]. Additionally, it allows the assessment of all types of qualitative data and is a good measure of transparency of research practice and reporting standards [19].

Although the studies were evaluated according to the CASP instrument, however, a cut-off score for paper exclusion was not set [18, 20]. Such value is arbitrary and not predetermined by the developers of the instrument. The decision to include or exclude a paper was discussed among the researchers and agreed upon mutually. Two reviewers (DT and RNR) independently appraised the included studies and then discussed the results jointly.

2.3. Data extraction and synthesis

The context of the studies was extracted by two reviewers (DT and RNR). The data extracted included objectives, demographics of the participants, criteria for diagnosis of TMD, method of data collection and method of analysis.

Further data extraction and synthesis followed the thematic synthesis approach developed by Thomas and Harden [21]. It involved line-by-line coding the data of the primary studies and organising the free codes into ‘descriptive themes’, which were then further interpreted into ‘analytical themes’ that composed the findings of the evidence synthesis.

A finding is defined as verbatim extract of the author’s analytical interpretation of the results or data. Data synthesis involved assembling the findings that had a similarity in meaning and categorising them to produce statements that represented that aggregation. These categories were then used to produce a set of synthesised findings. The themes were derived using an inductive iterative process, where the identified concepts were applied to subsequent studies, but new ones created when needed. All text under the heading “results” or “findings” was considered in the extraction and analysis. The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach was applied next. Confidence in the findings of a qualitative evidence synthesis is an “assessment of the extent to which a review finding is a reasonable representation of the phenomenon of interest” [22].

The review was registered on PROSPERO with the registration ID: CRD42020176820. It was reported according to the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement [23]

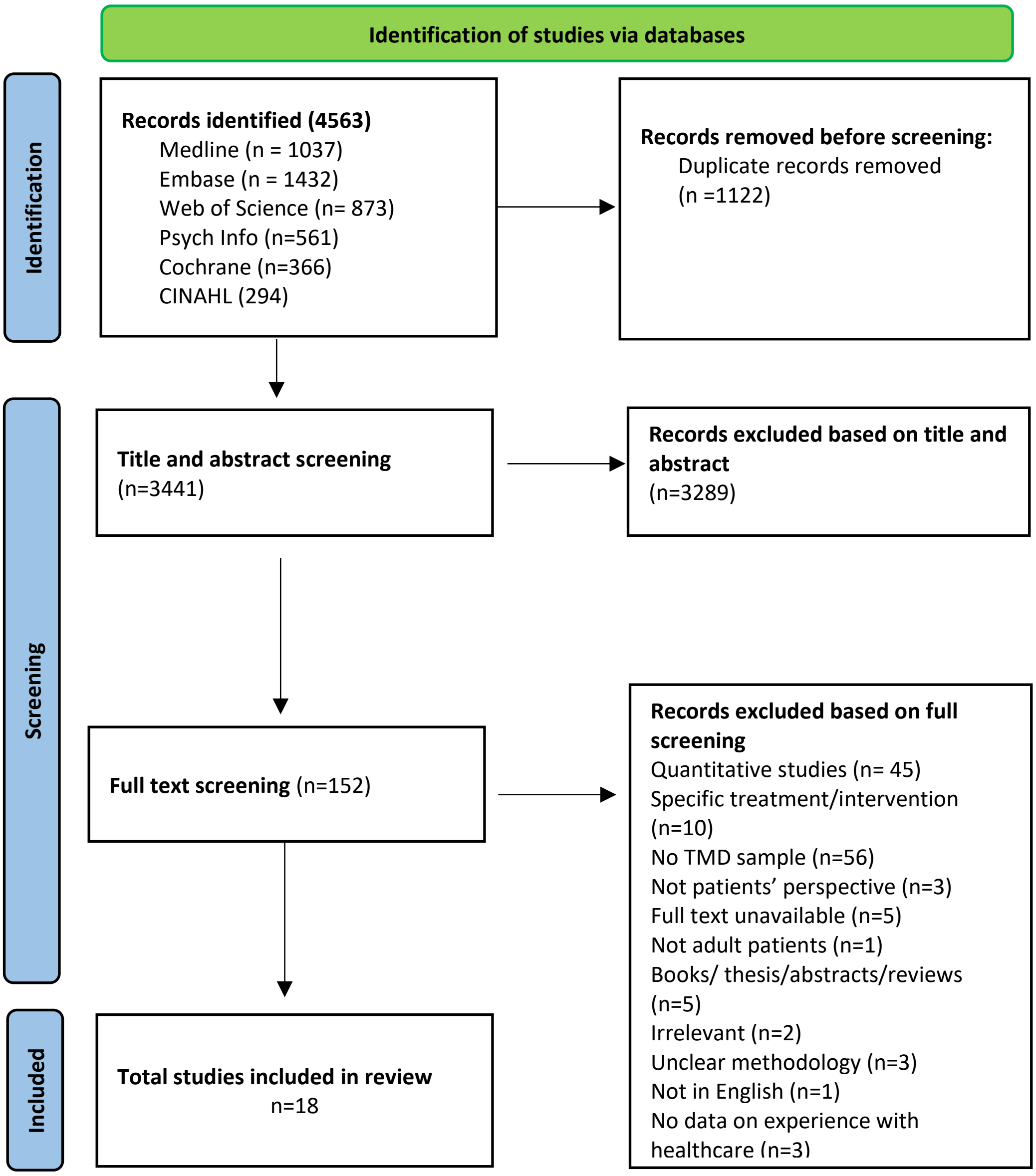
3. Results

3.1. Description of studies

The search based on the proposed strategies yielded 4563 articles across all databases. 3441 articles remained after removing the duplicates. After the first step of selection, which involved screening of the titles and abstracts, 152 papers were included for full text review. Following full text review, 18 studies were finally selected to be included in the qualitative evidence synthesis [8, 9, 24-39] . Figure 1 represents a flow chart of the selection process.

Two authors published two papers from the same population, as demonstrated by the identical sample size and distribution of males and females. All four papers were included in the review as the focus in these papers was different. Garro et al 1994 [38], and Wolf et al, 2006 [37] reported extensively on the patients’ experiences with healthcare, while Garro et al [30], 1994 and Wolf et al, 2008 [36] explored the experiences with TMD and the effect on daily life while still containing data relevant to this review. No studies were excluded based on quality. Table 1 shows the CASP appraisal of the included studies, table 2 shows a summary of the included studies, and table 3 shows the GRADE-CERQual evidence profile for each finding.

Figure 1. Flow chart of the selection process.



3.2. Findings and themes

3.2.1. Care seeking attitudes

The first theme describes the factors which drove TMD patients to seek medical help and the concerns they had regarding healthcare services.

The need for information

Patients looked for information online, from friends, textbooks and magazines [24-27]. However, the information received form health care professionals was deemed most trustworthy by some patients [24, 25]. They sought information to gain understanding of their condition, to help them cope with the pain, and to give guidance about where to seek care [24, 28, 39]. Acquiring information and answers gave the patients confidence and validated their experiences. Additionally, it was occasionally described as the most important part of management [39]

Validation of the pain experience

The pain experience was hard to articulate, and some patients were anxious of people believing they were exaggerating the symptoms [9, 24, 29, 36]. Therefore, they turned to the health care professionals to seek validation and legitimisation of their symptoms, as it entitled them to seek support and helped ease some of the anxiety [28, 30, 39] They also considered it a way to gain control and learn the tools to cope [39]

"I feel I have a legitimate complaint, that it's something that's not in my head. I know there is a physical reason for it" (Brenda, 37). [30]

"I had such vague complaints; I did not have the idea that this could have to do with my jaws. But when I came into the waiting room, I saw another guy rubbing his temples. Then I thought: I am not the only one; I'm not some kind of nutcase. I am at the right place." [interview 15]. [26]

"That did give me a lot more confidence because, one, he believes me; two, that I actually have a name to something. Because half the time when there's something that you think is

wrong, and no one believes you, and then all of a sudden, they say, “yes, it's got a name.” Well, you do feel better. 003” [39]

Patient characteristics

Some patients were more insistent than others on professional help. Personal traits may dictate that, such as catastrophising. Some patients found the pain very alarming and a top priority to address. Others were more confident in their own ability to self-manage, thought that seeking professional health was an exaggeration, or simply lost confidence in the health care providers. [26]

“To check if my complaint is something serious, I use the Internet, talk to friends, but I do not go to my general practitioner. I wish I could, but there is a lack of empathy.” [26]

“I went to see my general practitioner. I thought, maybe I have a brain tumour, maybe something is wrong.” [Interview 2]. [26]

Surrounding family and friends influenced the decision to seek professional help as well [9, 31]. This was mostly out of concern, but on occasions due to being irritated by some of the manifestations, such as repeated clicking sounds [31].

Nature of symptoms

Persistent or recent change in symptoms drove patients to seek medical help [39] . Ineffective pain control also prompted some to come back seeking other treatment options, or alternatively, caused disengagement from healthcare services [8, 26].

I am very close to actually going back now [to name of primary care practitioner], because it’s [the pain] starting [to increase again]. . . . I am going to [through] a few bits at the moment with stress and it’s [the pain] coming back how it was, and it’s really bad. I can feel it coming back. It [the jaw] clicks out of joint and then it hurts, but it’s [the pain] nowhere near as bad as it has been, but it’s only getting worse. (Q18, 12 mo). [8]

“Because there's no pain, there's not really much they (practitioners) can do because pain relief is generally the first thing… I think (if there was pain), it'd be a much higher priority from everyone in my life, doctors included, to find a solution. (par 010)” [39]

Concerns seeking health care

Some of the concerns which deterred patients from seeking professional help were the time and cost associated with dental visits. Cost was a significant concern, and some expressed frustration over the lack of insurance to cover TMD in some countries [38]. And the more clinicians they saw, the more concerned they were about the cost [25, 30, 32, 38]. Additionally, they faced the difficulty of finding the right caregiver, as they were uncertain who or where to ask for help [31, 39]. This may have caused delay in accessing effective management [39].

“It was my mom who said I should come here. I had no idea where I should go”. (P 1) [31]

“Taking time off is too much hassle.” [interview 7] [26]

The attitude of the clinician had an effect on the willingness to return for follow up visits [25-27] . Some reported distrust, lack of empathy on part of the clinical team, and expressed concern of the clinician suggesting psychological reasons for their pain [27, 29, 30, 38] . They also felt blamed when treatment was ineffective and chose to disengage from healthcare services. Therefore, losing confidence in the clinician and the treatment provided [25, 27, 38, 39] .

3.2.2. Expectations and health care experience

The second theme describes the general experience of TMD patients with healthcare, where they reported both positive and negative elements. Some patients came to the clinical appointment with a set of expectations, such as finding a cure, resolving the pain, receiving the long-sought information and diagnosis, undergoing scans and tests and being involved in the decision-making process [8, 24, 28, 29, 31, 33]. The interaction with the services could help the patients move forwards with the pain and adjust their views and expectations, or it could leave them feeling frustrated and more concerned than before.

Unsatisfactory clinical encounters

Some patients described their encounter in healthcare services as ambiguous, felt being passed around and unsupported, especially in primary care [9, 29, 34, 37, 39]. They also reported inadequate clinical discussions about their condition, difficulties in access to care, long waiting times in clinics, refusal of further appointments and seemingly inconsistent referral patterns [8, 9, 26, 27, 29, 31-33, 37, 39]. Patients reported referral to a range of specialities such as ENT, oral surgery, psychology and referral back and forth between primary and secondary care [8, 30]. Some had to insist on a referral and were declined because the practitioner was not convinced of their symptoms and refused to take the pain seriously [29, 33, 39]. The long waiting times to get an appointment or a referral reportedly worsened their symptoms, led to incomplete management, prolonged recovery, and exacerbated their concerns [9, 33, 39].

“Well, I felt terrible, especially when my GP [general medical practitioner] refused to refer me anywhere and told me I was a timewaster who was just imagining it. And, you know, not to bother him anymore.” (Sufferer 8) [33]

“And so I was in some intense pain . . . and it was so funny because as soon as I got to the doctors they tell me I should go to the dentist, and then as soon as I go to the dentist they tell me they can’t do anything for me, I have to go back to the doctors. And so it’s a lot of shifting back and forth, and I didn’t have a lot of time as a student and working full time and so . . . I’ve just kind of dealt with the pain”. (Lisa, 30). [32]

“An adequate interview was missing, no good questions.” [interview 11]. [26]

Patients’ characteristics and preconceptions were also factors that influenced the outcome of the clinical visit, as some came in with very specific hopes and expectations. Conflict with their pre-understandings sometimes led to rejection of information [24, 26]. Explanations and treatment plans incongruent with previous experiences and perceptions led to frustration and friction with the clinician [39].

“ . . . you don’t necessarily always want to tell them that they are in the wrong because they are the ones who are the doctors.” (participant 3, preconsultation) [24]

Pleasant experiences

Other patients however were content with their experience in healthcare. They discussed the benefits of the clinical visit in reducing their worry, impacting the relationship with the pain positively, helping put their mind to rest after ruminating endlessly about the symptoms and enabling them to abandon their pursuit for answers and invasive treatments. [24, 39]. Once satisfied with the explanations, they felt they could ‘get on with life’ [24].

“Even though I haven’t come away with a cure, I feel in a better position to cope with my symptoms.” (participant 4, postconsultation) [24]

“I guess what the appointment has done is drawn a line under it and made me think, well, that’s fine, but nothing can be done about it so I just need to get on with things.” (participant 5, postconsultation). [24]

Frequent clinical attendance

Another subtheme that emerged was the repeated clinical attendance for patients with TMD [9, 26, 30, 33, 38]. Possible reasons included: lack of diagnosis, lack of information, difficulty accepting the diagnosis, desire to be referred, lack of concordance between expectations and explanations of TMD, unresolved pain, dissatisfaction with the clinical visit, and the low self-efficacy of some patients and their need for ongoing care. This phenomenon emerged before and after receiving a diagnosis.

“I think for me the frustration initially was a lot of appointments [with varying primary care practitioners] but I wasn’t really getting anything from them because nobody was really—well I didn’t feel like they [the health care professionals consulted in primary care] were taking the whole situation very seriously”. (Q22, baseline) [8]

3.2.3. The patient-clinician interaction

The third theme describes the impact the healthcare professionals may have on the clinical experience. Interestingly, some patients appreciated the authoritative figure of the doctor. They welcomed being instructed what to do, as they considered the clinician best qualified to make the decisions [37, 39]. Others, however, preferred making informed decisions with clear explanations for potential treatment options [39]

" I can't do anything. . . . If the doctors can't tell me what I should do, then what should I do?" [37]

"When they (practitioners) give options, you can think about what the best option might be… I feel like sometimes people really need to provide you with all the facts rather than just offering you one thing. (006)" [39]

<u>Support and empathy</u>

'Good' clinicians were caring, knowledgeable and made the patients feel heard and understood [24, 37, 39]. Patients reported pleasant experiences when they were listened to and were given a thorough examination. This consequently encouraged trust in the information and diagnosis offered, even if scans and tests were expected. They trusted the proposed treatment and felt more able to self-manage [8, 9, 24].

"I felt the professor listened to me more than the other health care professionals I have seen and took into account the effects the pain was having on my life in general, rather than just treating me as a diagnosis." (participant 4, postconsultation) [24]

"I have faith in them [the GPs] and, and they're good in that they listen and they act on what you say in that they've never kind of gone oh you're talking rubbish about anything" (Q13, baseline) [8]

“I’m told by the professional, no it’s not that serious... he [dental consultant] filled us with confidence and he, like, I felt as if he knew exactly what he was doing, what he was [doing], you know, and gives us confidence” (Pt 23)[9]

Scepticism

Negative experiences were also described. Patients reported facing scepticism about the authenticity and severity of the complaints, disinterest, the implication that they were imagining their pain and seeking attention. They also reported limited time given discussing the problem and refusal to refer [8, 9, 25-27, 29, 33-38]. This attitude caused them to feel dismissed and therefore affected their willingness to accept the information offered by the care provider. It also discouraged them from seeking further treatment with them [24, 25, 27]. Interestingly, this was also reported by some patients with symptoms of hypermobility, locking and clicking of the jaw. [27]

Patients sometimes overcame vulnerability with anger, where they became demanding and argumentative [37] . They reported accepting the authority of the doctor but not necessarily their advice [24].

“*I was badly treated at the clinic. The dentists who work there thought I was a “psych” case and that I needed something. They said:” There is nothing wrong with you, it is all in your head. Just calm down and get some psychiatric help instead.” It isn’t fun to hear such things”.* [37]

“The dentist also thought it was nice to include my private life in his analysis. He said: “You have such personal problems. You must understand that you are under pressure.” Such statements make me crazy. Don’t sit there and tell me what problems I have! I’ll take care of that best myself!” [37]

Some patients also reported lack of diagnostic certainty on the part of the clinician, especially in primary care. They described receiving partial explanations which amplified their worry. [8, 30, 33, 35]

"What kind of a doctor could there be who would understand this? I've looked high and low." [35]

"I've been to see them all [dental and medical professionals]. The GPs don't seem to know what to do. I just don't know where to go next. I go to GPs and they just give me more tablets and that's it" (Q12, 12 mo). [8]

3.2.4. Diagnosis as a stepping-stone for improvement

The fourth theme describes the importance of receiving a diagnosis for patients with TMD. A delay or even lack of diagnosis was a common theme among the examined studies. Patients reported seeing many practitioners before obtaining one and mentioned receiving multiple diagnoses as well. This delay was frustrating and evoked anxiety and fear that the pain was signalling something sinister [24, 31, 33, 34]. The lack of diagnosis also caused uncertainty, self-doubt about the legitimacy of the complaint, failure to progress, and construction of own explanations to the symptoms [8, 9, 29-31, 34, 38]. In some instances, patients were more concerned with the diagnosis than the treatment options. [9]

"Why a diagnosis would help me is because my mind, since 1987, has been, shall we say, in a bit of turmoil. I think, "What is happening inside my head? Have I got a tumour?" etc., etc." [8]

"I got panic-stricken. I didn't know what was going on". (P-2) [31]

"I wasn't necessarily thinking of the cure, more of knowing what was wrong with the jaw. That was, I think, the primary thought in my mind was I wanted to know what this was. And then I think the cure was second" (Pt 15) [9]

Receiving a diagnosis was emphatically mentioned by many of the patients as a very important step in their pain journey. They felt elated and reassured as it gave legitimacy to the complaints, acknowledged their illness, and confirmed they are "not the only one". It also empowered them to ask questions and look for information about the condition. They mentioned the importance of diagnosis in ceasing the exhausting search for answers, initiating self-coping strategies, and giving entitlement to seek support. [9, 24, 30, 33, 34, 38].

"I mean you had a name for it and you knew you weren't alone with it so it eased your mind totally really knowing that it wasn't anything too serious." (Sufferer 7) [33]

It also meant receiving the right information about the condition and initiating discussions about the treatment options. Hence, it could help manage the expectations and the long-term prognosis [32, 33].

"You want a magic wand waved over and then it's [the pain's] gone...Then reality kicks in and you think no that's in never never land, that's not the way it works." (Sufferer 13) [33]

3.2.5. Management

The fifth theme describes the different management strategies offered to the patients. Treatment in general was not sought if the symptoms were mild, or if they did not interfere profoundly with life [28]. In other cases, however, patients were very persistent in finding the treatment, and this search intensified with increasing pain and intrusion on daily life [30].

Management was reported to be inconsistent and inappropriate at times resulting in ineffective pain control [8, 28, 30, 33]. Furthermore, treatment was sometimes offered without reaching a firm diagnosis first, and mainly included pain killers [8, 29, 33, 35]. Unmet treatment needs had financial and emotional consequences for the patients [39]

"I think it [the pain and problems] got worse in a sense. And I was probably becoming more distressed because I thought that once the tooth was taken out, and that was a big step to have something like that removed, that it would be okay [the pain and problems would be resolved]." (Sufferer 3) [33]

On occasions, treatment plans consisted of multiple attempts till the effective modality was found [8]. A range of management approaches were offered to treat TMD with varying degrees of success such as: oral splints, physiotherapy, acupuncture, biofeedback, dental work, orthodontic treatment and surgery [8, 29-32, 35, 38]. Some expressed difficulties in making treatment decisions, as different explanations were offered with different treatments [38]. Medications were also offered but many patients voiced concerns over the frequent use of analgesics. They were concerned about the side effects and drug interactions with other medications; hence did not use them unless in severe pain. Additionally, they expressed concerns over the effectiveness, as they reported them not to be useful or with declining effectiveness over time [25, 29, 31, 32].

"I mean the jaw pain if you take strong painkillers it gets under control but I can't just do that all the time. Painkillers make me slow. It's so nerve-wracking and stressful, especially when I have an exam coming up". [29]

"I've had oral splints. I've tried several of them, but I don't know that I've gotten any better." [35]

Self-management strategies were also frequently reported, such as: physical activities, jaw stretching exercises, meditation, yoga, distraction techniques, hot or cold compresses, and making lifestyle changes [8, 25, 26, 29, 31, 32, 34]. Patients expressed that the ability to self-manage is associated with their knowledge about the illness, the triggers, its fluctuating course, confidence in the clinician, and reduction in pain and dysfunction levels that they were able to manage on their own. They also reported getting better at self-management over time [8, 9].

" I've got to the point now where I think I've got to do it because I can only help myself now, it's not a case of...I could come here for the next 12 months but unless I continue to help myself it's not going to get any better as well" (Pt 16) [9]

Lack of education on the proper methods to self-manage may result in patients undertaking harmful practices to relieve the pain. It might also lead to uncertainty on the part of the patients about which strategies are useful [24, 34].

3.2.6. Social support

The sixth theme describes the patients' attitudes towards the social support needed from surrounding people.

Support groups

Social networks were reportedly important for patients with TMD. They welcomed being informed of support groups as it confirmed that they were not alone. They appreciated the knowledge shared and helped them set realistic expectations. [27].

"Maybe then [if I had a diagnosis] there are things I can do, like support groups. I don't even know if I would want to go to one, but knowing that they are there, that there is an option, some sort of community spirit thing." (participant 4, preconsultation) [24]

Family and friends

As for the support sought from family and friends, patients had contradictory attitudes. Some sought that support and highlighted the positive effects it had on coping and survival [25, 27, 31]. Whereas others preferred to suffer in silence and kept the pain to themselves. They did not want to burden anyone with the pain or assume the identity of a chronic pain patient [25, 29, 31, 32].

"If I had not had animals, family, and a boyfriend, I wouldn't have survived." (P-4) [31]

"I don't really talk to them [friends] about my pain. I don't really like to explain about the pain. I guess I'm scared that they wouldn't understand". (Interviewee 2) [29]

"No reason to concern anybody else and have anybody else get upset about it. Uh, no, I just put up with it, that's all". [32]

Discussion

To our knowledge, this is the first qualitative systematic review focussing on the experience of TMD patients within the healthcare services. In our appraisal of the quality of the included studies using the CASP checklist, none of the studies were excluded based on quality. One point of debate currently found in the literature is the need to appraise the quality of qualitative research [40]. Some qualitative researchers suggest that those studies should not be viewed in the same light as quantitative research. It is argued that the basic epistemological and ontological assumptions of quantitative and qualitative research do not match, therefore, measures such as validity should not be applied to qualitative studies [41, 42] . Nevertheless, other researchers claim that, indeed, some studies may be more rigorous and well conducted than others. Therefore, should be subject to critical appraisal [43]. The Cochrane guidance currently states that the assessment of methodological limitations for the purpose of systematic reviews and evidence synthesis remains essential, even when studies are not to be excluded on the basis of quality [44, 45]. Given that there are no accepted rules for the exclusion of studies based on quality [21], none were excluded on this basis in the review. Interestingly, most of the papers did not discuss the influence of the interviewer on the participants (item 6 of CASP checklist) or what is known as reflexivity in qualitative research. This transparency in describing the intersecting relationships between the researcher and the participants increases the credibility of the findings and enables a deeper understanding of the work [46].

Similar reviews were found elsewhere in the literature for chronic pain conditions, such as rheumatoid arthritis [47, 48], chronic non-malignant musculoskeletal pain [49, 50] and low back pain [51]. Strong similarities in findings were identified, which suggests that despite the localised nature of TMD, it may interfere with the daily lives of patients as significantly as systemic chronic pain conditions.

A growing body of evidence highlights the importance of a pleasant clinical experience to patients. It is not only expected, but also humane [52]. Previous reviews of chronic pain conditions have revealed an element of dissatisfaction with the healthcare services [49, 53-55]. Patients may struggle to negotiate the system and often feel like a "shuttlecock" due to the constant referrals back and forth between different components of the healthcare system [49]. TMD patients seem to share this problem too. They mentioned repeated clinical attendance due to various reasons, such as lack of diagnosis, lack of information and dissatisfaction with the clinical visit. Some reports in the literature also highlight the uncertainty of primary care dentists and GPs in managing orofacial pain [56] [34]. This is likely due to insufficient exposure to TMD problems in their undergraduate studies, or lack of the set of skills to manage patients with TMD during subsequent postgraduate training [34]. Regardless of the cause of the hesitation in the diagnosis and management of patients with TMD in primary care, this can lead to onward referral to more than one specialist service and hence the 'shuttlecock' experience for patients. The participants in this review did not highlight a distinction between GPs and dentists as first point of contact, and any effect this might have had on the overall clinical experience. Peters et al, however, noted in their qualitative study of dentists, GPs and patients, that GPs felt responsible for these patients and tried to avoid 'yo-yoing' them between dental and medical services. GPs were also more open to using psychological approaches to management [34]. Aggarwal et al also reported in their study, that indeed, most general dental practitioners correctly diagnosed COFP, however, there seemed to be variation when it came to management strategies and referral patterns in primary care [57]. The medical-dental divide is also discussed as an obstacle to effective TMD care. For example, in the US, dentistry and medicine have separate systems in terms of practice and financing arrangements [58]. Both type of practitioner is more likely to focus on the symptoms of TMD which fall within their area of training, and it usually falls to the patients to navigate and coordinate between multiple healthcare professionals [58].

The importance of receiving a diagnosis was highlighted strongly in this review. It was described previously by Toye et al as a "quest for the holy grail", where patients need it in order to validate their pain experience and begin the quest for pain control [53]. It is highly valued and integral to a sense of credibility. Without a firm label to the pain, doubt permeates familial and social relationships and creates powerful emotions such as fear, agitation and guilt [49]. Patient education and reassurance are important in the context of chronic pain as well. They form the 'cornerstone' of back pain management according to the International Association for the Study of Pain (IASP), and are the first-line management approach for musculoskeletal pain [59]. Some misconceptions are commonly associated with chronic pain, however, such as the necessity of imaging to diagnose pain conditions, and that activities should be avoided when in pain [60, 61]. Therefore, effective discussion about the patients' expectations, fears and beliefs is encouraged, as it may work to empower patients, alleviate their concerns, allow them to develop the essential skills to manage their pain and decrease dependency on healthcare professionals [59]. Different modes can be utilised to deliver education, such as verbal discussions, written material (leaflets and pamphlets) and audio-visual aids. Several benefits were also reported in association with group management strategies [62, 63], where the patients found these sessions helpful in learning new information, skills, coping techniques, and knowing they were not alone. [63]

Health professionals play an important role in coping with the pain as well. Chronic pain patients have expressed the need to be believed, listened to and treated with dignity [53]. These features forge a trusting relationship with the patients and are integral to their ability to self-manage [55]. TMD patients in this review felt strongly about the importance of being looked after by an understanding and empathic clinician. It might make them more receptive of information, and more able to cope with their symptoms. Doyle et al also reported in their systematic review a positive association between patient clinical experience and self-reported outcomes, adherence to treatment instructions and medications, and better use of preventive care [52].

Durham et al have suggested a clinical journey map for patients with TMD. A potential application of this map is to identify the time points in clinical care where introducing intervention would be most useful. They suggest that the life effects of TMD could be reduced if standardised conservative therapy is introduced early in primary care alongside early diagnosis. This helps in establishing a perceived control over the condition and could also aid decreasing the burden on secondary care in terms of managing these patients [9].

Multiple studies have explored the barriers to healthcare in different countries [64-67]. Some of the factors revealed, paralleled our results such as: unfavourable evaluation of medical care, some personality traits, in addition to the traditional barriers, such as access, time and cost of care. These shared barriers confirm that such healthcare problems are not exclusive to COFP patients but span different fields and different countries. Our results suggest that long waiting times to get an appointment or a referral might inflame the patients' anxiety, worsen their symptoms, and possibly make them more prone to self-constructed explanations to the pain. And once some preconceptions take hold, it might be difficult to persuade some patients otherwise.

Limitations

Although the literature search was conducted systematically and rigorously, the authors cannot confirm that all the relevant studies have been included, as the focus was on articles published in the English language in the six aforementioned databases. Grey literature was also not included, which may have introduced some publication bias.

Sensitivity analysis was not formally conducted to assess whether the exclusion of the studies with lower CASP scores might have changed the results. However, as shown in the GRADE-CERQual evidence profile, no major findings were supported exclusively by such studies. Hence, it is not suspected that omitting these studies would have affected the results remarkably.

Although many participants in the included studies had a combination of TMD diagnoses, the majority reported the presence of pain. Therefore, TMD patients with no associated pain may have been under-represented, and caution is advised when applying the findings to all TMD patients. It is also worth mentioning that only a minority of patients with signs and symptoms of TMD present for treatment [2].

Qualitative evidence synthesis by default requires researchers to interpret concepts, which may be influenced by their pre-existing ideas. However, the concept of ‘going beyond’ the original studies has been identified by some as the hallmark of this type of synthesis [21, 68]. And while the interpretations in this review may not be the only way to view the data, we ensured that individual interpretations remained grounded within the experience of the original studies [49]. Some may also argue against qualitative systematic reviews on the grounds that they de-contextualise the findings of the primary studies [21, 69]. We attempted to preserve context in this review by presenting a summary of each primary study, so the readers can judge the transferability of the findings to their own setting.

Conclusions

The effects of TMD on the patients’ lives range from minimal to debilitating. In consequence, patients may become anxious, depressed, and melancholic. Thus, when this is combined with the problems within healthcare – especially primary care- an unpleasant encounter could arise for both parties. Ongoing research have already identified some problems within the pathway of healthcare for COFP patients and suggest that the current pathway does not meet the patients’ needs. Further research is needed to determine the parts of healthcare experience which potentially have the most effect on patient reported outcomes, and to quantify these effects in order to maximise the effectiveness of financial resources in correcting these problems.

Highlights

- The journey within the healthcare services could play a valuable role in the ability to cope with chronic TMD.
- Receiving a firm diagnosis, being listened to, and believed are important factors in the clinical experience.

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Table 1. CASP appraisal

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Durham et al (2010) [33]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Mienna et al (2014) [35]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Bonathan et al (2014) [24]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Au et al (2014) [25]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Rollman et al (2013) [26]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Peters et al (2015) [34]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Breckons et al (2017) [8]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Hazaveh et al (2018) [29]	Y	Y	Y	Y	Y	CT	Y	Y	Y	Valuable
Fjellman-Wiklund et al (2019) [28]	Y	Y	CT	CT	CT	N	Y	Y	Y	Unclear for qualitative part.
Nilsson et al (2016) [31]	Y	Y	Y	Y	Y	CT	Y	Y	Y	Valuable
Durham et al (2011) [9]	Y	Y	Y	Y	Y	N	Y	Y	Y	Valuable
Eaves et al (2015) [32]	N	Y	CT	CT	Y	N	Y	CT	Y	Yes/ somewhat valuable
Wolf et al (2006) [37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable
Wolf et al (2008) [36]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable
Garro et al (1994) [38]	Y	Y	Y	Y	Y	N	N	CT	Y	Yes/ somewhat valuable
Garro et al (1994) [30]	N	Y	N	Y	CT	N	N	CT	Y	Yes/ somewhat valuable
Ilgunas et al (2020) [27]	Y	Y	Y	Y	Y	CT	Y	Y	Y	Valuable
Dinsdale et al (2022)[39]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Valuable

Y: Yes. N: No. CT: Cannot tell.

Table 2. Details of included articles.

Author	Country	Aim	Sample size	Age	Gender	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Durham et al (2010) [33]	UK	To describe the difficulties that sufferers of TMDs encounter in obtaining a definitive diagnosis of their condition and to examine critically the impact this has upon them.	19	18-60	14F, 5M	TMD (Suffering from pain, i.e., myofascial pain and arthritides, and those suffering from mechanical dysfunction due to disc displacement	Research Diagnostic Criteria for TMD (RDC/TMD)	Specialist oral and maxillofacial surgery and restorative dentistry clinics.	Semi-structured individual interviews	Constant comparative method (Glasser, 1965). Line-by-line coding inductive and iterative to develop theory.
Mienna et al (2014) [35]	Sweden (arctic circle)	To explore thoughts, experiences, and beliefs regarding temporomandibular disorders (TMD) among Sami women with and without TMD in order to gain insights into their health care experiences and to generate a hypothesis regarding factors associated with long-standing TMD	17 (10 with TMD+7 healthy)	23-58	All F	TMD	RDC/TMD	-	Individual interviews	Grounded theory
Bonathan et al (2014) [24]	UK	To explore patients' understanding of their orofacial pain	12	26-73	9F, 3M	COFP of non-dental origin (including TMD)	-	Orofacial pain clinic.	Individual semi-structured interviews (face to face and telephone) + narrative letter	Thematic analysis

Au et al (2014) [25]	Hong Kong	To explore the perceptions and experiences of southern Chinese community dwelling elderly people living in Hong Kong with chronic OFP symptoms and their treatment seeking behaviour.	25	65-83	21F, 4M	Non-dental OFP (including TMD)	-	Attendees at daytime social and community centres	Semi-structured individual interview	Thematic Framework Approach that involved a multi-stage thematic analysis
Rollman et al (2013) [26]	The Netherlands	To assess possible differences between care seekers and non–care seekers with TMD pain complaints through the use of semi-structured interviews.	16	Mean age for non-care seekers 38.9, for care seekers 37.5	12F, 4M	TMD	-	The subjects were selected from a larger survey study	Semi-structured individual interviews	Constant comparative analysis and qualitative content analysis. Followed by a Delphi consensus method.
Peters et al (2015) [34]	UK	To understand patients', GPs', and dentists' experiences of COFP and identify what barriers may exist to improving psychological management within dental and medical services.	7	17-56	5F, 2M	Persistent jaw pain	-	Secondary and tertiary care dental and specialist facial pain clinics	Face-to face individual semi-structured interviews	Constant comparative approach and drawing on the principles of grounded theory.
Breckons et al (2017) [8]	UK	The aim of this qualitative study was to critically examine patients' journeys through care, identify their experiences of the care pathway, and use these findings to help explain some of the findings in the cost analysis of the care pathways that ran	22 (18 for a second interview)	<40 - >70	17F, 5M	Persistent OFP of non-dental origin (including TMD)	-	-	Telephone/ face to face semi-structured interviews	Iterative thematic analysis

		concurrent to this substudy (Durham et al. 2016)								
Hazaveh et al (2018) [29]	Canada	The study aimed to explore this area [the experience of living with COFP and to gain a deeper understanding of the common elements affecting the lives of chronic pain sufferers.	6	27-68	1M, 5F	OFP of non-dental origin (Including jaw pain)	-	Pain Clinic	In-depth individual interviews	Phenomenological approach based on the reading approaches (developed by Van Manen)
Fjellman-Wiklund et al (2019) [28]	Sweden	To identify predicting factors for perceived treatment need among adult individuals who screened positive to the 3Q/TMD and to explore individuals' thoughts and experiences related to treatment of their TMD complaint	300 (140 randomly selected 3Q-positives and 160 age- and gender-matched 3Q-negatives)	20-69	201F, 99M	TMD	RDC/TMD	Public Dental Health Service	Written questionnaire	Qualitative content analysis (manifest interpretations)
Nilsson et al (2016) [31]	Sweden	To explore adolescents' explanations of their temporomandibular disorder (TMD) pain, their pain management strategies for TMD pain, and their treatment- seeking behavior.	21	15-19 (Mean age 17.2)	19F, 2M	TMD	RDC/TMD	Orofacial pain clinic	Semi-structured individual interviews	Qualitative manifest content analysis with an inductive approach.
Durham et al (2011) [9]	UK	To develop a robust empirically derived map of TMD sufferers' journey through care	29	18-65	23F, 6M	TMD	Diagnosis by criteria derived from the research diagnostic criteria	Dental hospital	Semi-structured individual interviews	Constant comparative method and thematic analysis

Eaves et al (2015)[32]	US	Aims not clear.	95 did baseline interview/ 44 did 4 or 5 interviews (a total of 271 interviews)	18-69	-	TMD	RDC/TMD	Community outreach and newspaper advertisements	Semi-structured, open-ended interviews	Not stated – Interviews were transcribed verbatim and coded. Basic code structure consisted of a set of themes.
Wolf et al (2006)[37]	Sweden	To use a qualitative research study to analyze the experiences of patients with nonspecific chronic orofacial pain with respect to consultations for their pain condition.	14	21-77	11F, 3M	Chronic non-specific OFP (including jaw pain/TMD)	RDC/TMD	Orofacial Pain Unit	Individual thematic in-depth interviews	Qualitative phenomenological approach
Wolf et al (2008)[36]	Sweden	To analyze the nonspecific chronic orofacial pain patient's experience of the pain condition and to gain knowledge on the complexity of the problem.	14	21-77	11F, 3M	Chronic non-specific OFP (including jaw pain/TMD)	RDC/TMD	Orofacial Pain Unit	Individual thematic in-depth interviews	Qualitative research strategy based on phenomenology.
Garro et al (1994)[38]	US	This article provides, from the perspective of TMJ support group members, a description of this condition and the experiences of these individuals in living with and seeking care for a controversial condition within the context of the American health care system	32	23-69	27F, 5M	TMD	Self-reporting of the diagnosis of TMD	"TMJ" support groups	Open ended semi-structured interviews	Not stated – A framework of events and themes was filled out during the interviews.

Garro et al (1994) [30]	US	Aims not clear.	32	23-69	27F, 5M	TMD	Self-reporting of the diagnosis of TMD	Support group members	Open ended, semi-structured interviews	Not stated - Interviews were taped, transcribed, and content analysed with recurring themes noted.
Ilgunas et al (2020) [27]	Sweden	To explore the young adult's daily life experiences of GJH, particularly concerning jaw function and their experiences of medical and dental care providers	9	18-22	8F, 1M	TGJH and MD	Beighton score for hypermobility - none for TMD	Department of Clinical Oral Physiology	Semi-structures individual interviews.	Qualitative content analysis and inductive approach
Dinsdale et al (2022)[39]	Australia	This study aimed to qualitatively investigate i) the experience of individuals seeking professional care for persistent intra-articular TMD and ii) key management needs and preferences of this population	13	22-61 (Mean age 32.7)	12F, 1M	Intra-articular TMD	DC/TMD	Flyers placed in community-based clinics waiting rooms + social media advertisement (Facebook)	Semi-structured interviews conducted 1:1 via Zoom	Essentialist thematic approach

Table 3. CERQual GRADE evidence profile for review findings

Summary of review finding	Studies contributing to finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual overall assessment
1. The need for information: Patients sought information from different sources. They needed information to understand their condition and be able to cope better with the pain.	6 studies [24-28, 39]	Minor concerns (1 of the 6 studies has low CASP)	No or very minor concerns	No or very minor concerns.	Minor concerns (2 studies have a sample of TMD in addition to other COFP conditions, 1 of which consisted of elderly patients).	High confidence
2. Validation of the pain experience: it entitled patients to seek support and helped ease their anxiety, especially if surrounding people believed they were exaggerating the symptoms.	6 studies [9, 24, 28-30, 39]	Minor concerns (2 of the 6 studies have low CASP)	No or very minor concerns	Minor concerns (the finding Is complex and could be explored in more detail)	Minor concerns (2 studies had a TMD sample in addition to other COFP conditions).	Moderate confidence
3. Patient characteristics: some personal traits may influence the choice to seek professional help such as catastrophizing.	1 study [26]	Very minor concerns	No or very minor concerns	Moderate concerns (supported by 1 study only)	No or very minor concerns	High confidence
4. Nature of symptoms: Persistent or recent change in symptoms drove patients to seek medical help.	3 studies [8, 26, 39]	Very minor concerns	No or very minor concerns	Moderate concerns (supported by 3 studies only)	No or very minor concerns (1 study had a TMD sample in addition to other COFP conditions).	High confidence
5. Concerns seeking professional help include cost, time, finding the right caregiver, and the attitude of the clinician.	8 studies [25-27, 30-32, 38, 39]	Minor concerns (2 of the 8 studies have low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (1 study had a sample of TMD in addition to other COFP conditions and consisted mainly of elderly patients. 1 study consisted of adolescent patients).	High confidence
6. Patients were unhappy with the healthcare services if they felt unsupported, passed around, were not given enough time and waited a long time for appointments.	11 studies [8, 9, 26, 27, 29, 31-34, 37, 39]	Minor concerns (1 of the 11 studies has low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (3 studies have a TMD sample in addition to other COFP conditions. 1 study consisted of adolescent patients).	High confidence

7. Patients who were content with the clinical visit reported reduced anxiety, better relationship with the pain and abandoned their search for information and invasive treatments.	2 studies[24, 39]	Very minor concerns.	Moderate concerns (This finding is complex and if explored further, contradictory patterns may emerge)	Moderate concerns (The finding is complex and further exploration is needed)	No or very minor concerns (1 studies have a TMD sample in addition to other COFP conditions).	Moderate confidence
8. Repeated clinical attendance to healthcare services was due to lack of diagnosis, unresolved pain and dissatisfaction with the clinical visit.	5 studies[9, 26, 30, 33, 38]	Minor concerns (1 of the 5 studies have low CASP)	No or minor concerns.	No or very minor concerns.	No or very minor concerns.	High confidence
9. The patient-clinician interaction: negative clinician attitude was sometimes reported. It affected the patients' willingness to accept information and discouraged them from seeking further treatment.	13 studies[8, 9, 24-27, 29, 30, 33-35, 37, 38]	Minor concerns (1 of the 13 studies have low CASP)	No or minor concerns.	No or very minor concerns.	Moderate concerns (5 studies have a TMD sample but in addition to other COFP conditions. 1 of which consisted of elderly patients. 1 study consisted of Sami women).	High confidence
10. The patient-clinician interaction: understanding and empathic clinicians induced trust in the information and treatment given. It also helped with the ability to self-manage.	3 studies[8, 9, 24]	Very minor concerns	Minor concerns (Additional patterns may emerge if explored further)	Minor concerns (Effects of a positive clinician attitude needs to be explored more thoroughly)	Minor (2 studies have a TMD sample in addition to other COFP conditions).	Moderate confidence
11. Diagnosis was important for improvement: diagnosis validated the pain experience, helped in abandoning the search for answers, helped in initiating self-coping strategies and gave entitlement to seek support.	7 studies[9, 24, 30, 32-34, 38]	Minor concerns (2 of the 7 studies have low CASP)	No or very minor concerns	No or very minor concerns	No or very minor concerns (1 study has a TMD sample in addition to other COFP conditions).	High confidence
12. Management: a range of treatment options were offered with varying degrees of success. They were occasionally inconsistent or inappropriate	9 studies[8, 28-33, 35, 38]	Minor concerns (3 of 9 studies have low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (2 studies have a TMD sample in addition to other COFP conditions. 1 study consisted of Sami	High confidence

which led to ineffective pain control.					women. 1 study consisted of adolescent patients).	
13. Seeking support: patients appreciated being told about support groups.	2 studies [24, 27]	Very minor concerns	No or very minor concerns	Moderate concerns (supported by 2 studies only)	No or very minor concerns (1 study has a TMD sample in addition to other COFP conditions.	High confidence
14. Family and friends: while some patients relied heavily on family and friends' support to cope with the pain, others preferred to deal with the pain on their own. They did not want to burden them with their pain or assume the identity of a chronic pain patient.	5 studies [25, 27, 29, 31, 32]	Minor concerns (1 of 5 studies has low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (2 studies have a TMD sample in addition to other COFP conditions. 1 of which consisted of elderly patients. 1 study consisted of adolescent patients).	High confidence

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