A Meta-Synthesis of the Experience of Chronic Temporomandibular Disorder Patients Within Health Care Services

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Aims: To systematically review the qualitative evidence related to experiences of patients with temporomandibular disorders (TMD) and to explore their journeys within health care services. **Methods:** A systematic search of the following databases was conducted: MEDLINE, Embase, PsycINFO, Web of Science, CINAHL Complete, and the Cochrane database. Thematic synthesis was used to analyze and synthesize the data from qualitative studies that explored the journeys of TMD patients within health care services. The Critical Appraisal Skills Programme (CASP) tool was used to critically appraise the quality of the included studies. **Results:** The search strategies yielded 4,563 articles across all databases, and 18 articles were eventually included. Six themes were derived: care-seeking attitudes; expectations and health care experience; the patient-clinician interaction; diagnosis as a stepping stone for improvement; management; and social support. **Conclusion:** The journey within health care services may play a valuable role in the ability to cope with chronic TMDs. Receiving a diagnosis, being listened to, and being believed are among the most important elements making for a positive clinical experience. *J Oral Facial Pain Headache 2023;37:55–73. doi: 10.11607/ofph.3112*

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Temporomandibular disorders (TMDs) is a collective term embracing a number of clinical problems that involve the masticatory musculature, the temporomandibular joint (TMJ) and associated structures, or both.[1] It is a common condition that may affect up to a third of the general population.[2] Symptoms range from pain in and around the TMJ and surrounding muscles to functional changes such as limited mouth opening and deviation of mandibular movements. Patients with TMDs 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 health care 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 patient views on management strategies.[7] This may result in unmet patient expectations and promote excessive use of health care services to help cope with the pain. Breckons et al additionally suggest that the current health care pathways for chronic orofacial pain patients in the United Kingdom do not appear to meet patient needs,[8] resulting in multiple unnecessary consultations and increased use of health care resources.[9]

Patient-centered care (PCC) is a way to empower patients and expand their role in health care. The aim of this approach is to provide patients with reassurance, comfort, support, legitimacy, and confidence.[10] PCC therefore assumes that patients are capable of deciding what happens to their own bodies, and the role of clinicians is to support them with advice and delivery of health care in line with their needs.[11] Government bodies and policy makers around the world are increasingly recognizing the importance of PCC along with the merits of a pleasant hospital experience for patients.[12–14] In the United Kingdom, the

National Health Service (NHS) has identified the 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 detailing the elements that are critical to patient experiences of NHS services. Some of these elements are respect for patient-centered values, emotional support, coordination of care, and providing enough information.[15]

Several qualitative studies have provided insight into the experiences of TMD patients with health care services. Qualitative evidence synthesis, however, can offer greater understanding by bringing together the available research on this topic. It can also help inform practice and provide care that meets the patients' needs, as recounted by them.[16] To the present authors' knowledge, there is no qualitative review focusing on the experiences of TMD patients within health care services. Thus, the aim of this study was to systematically review and synthesize the available qualitative evidence related to the experiences of TMD patients within health care to highlight the important aspects of care and explore the difficulties encountered.

Materials and Methods

The keywords for the search were based on the SPICE (setting, perspective, phenomenon of interest, comparison, evaluation) 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 for the present study were as follows: setting = health care; perspective = patients; phenomenon of interest = TMDs; comparison = none; evaluation = patient experience/satisfaction.

The search strategy aimed to locate all available articles and involved three steps. First, an initial search was run using MEDLINE and Embase to identify MeSH terms and keywords describing the 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*)

Second, 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, a manual search of the reference lists of the included articles was performed for additional studies that may have been missed from the previous search. The full search strategy can be found in Appendices 1 to 4.

Study Selection

The studies eligible for inclusion were qualitative studies reporting on the aspects of TMD patient experiences within health care services. Mixed-method studies were included if they contained a qualitative component that was separate from the quantitative component. Studies including 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 findings that were not attached to a particular pain condition. This approach was used because the findings of the relevant studies applied to the various COFP conditions under investigation, including TMDs. The findings and quotes that were assigned to another pain condition, such as persistent idiopathic facial pain or trigeminal neuralgia, were excluded from the analysis. This method was adopted because focusing solely on papers with a pure sample of TMD patients 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 years (as this is the age when children transition into adult health care services in the UK) and were written in English. Studies were excluded if they focused on experiences with a specific treatment or intervention, if they did not contain data regarding the experience within health care, or if the full text was unavailable.

Critical Appraisal of the Studies

The review process was undertaken in two stages by two reviewers (D.T. and R.N.R.). First, the titles and abstracts of the results were screened against the inclusion and exclusion criteria. Articles that met the inclusion criteria moved to the second stage, review of the full article. The final decision to include articles in the review was made after discussion among the author group.

The Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist was used to appraise the methodologic 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 Organization (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, a cut-off value for paper

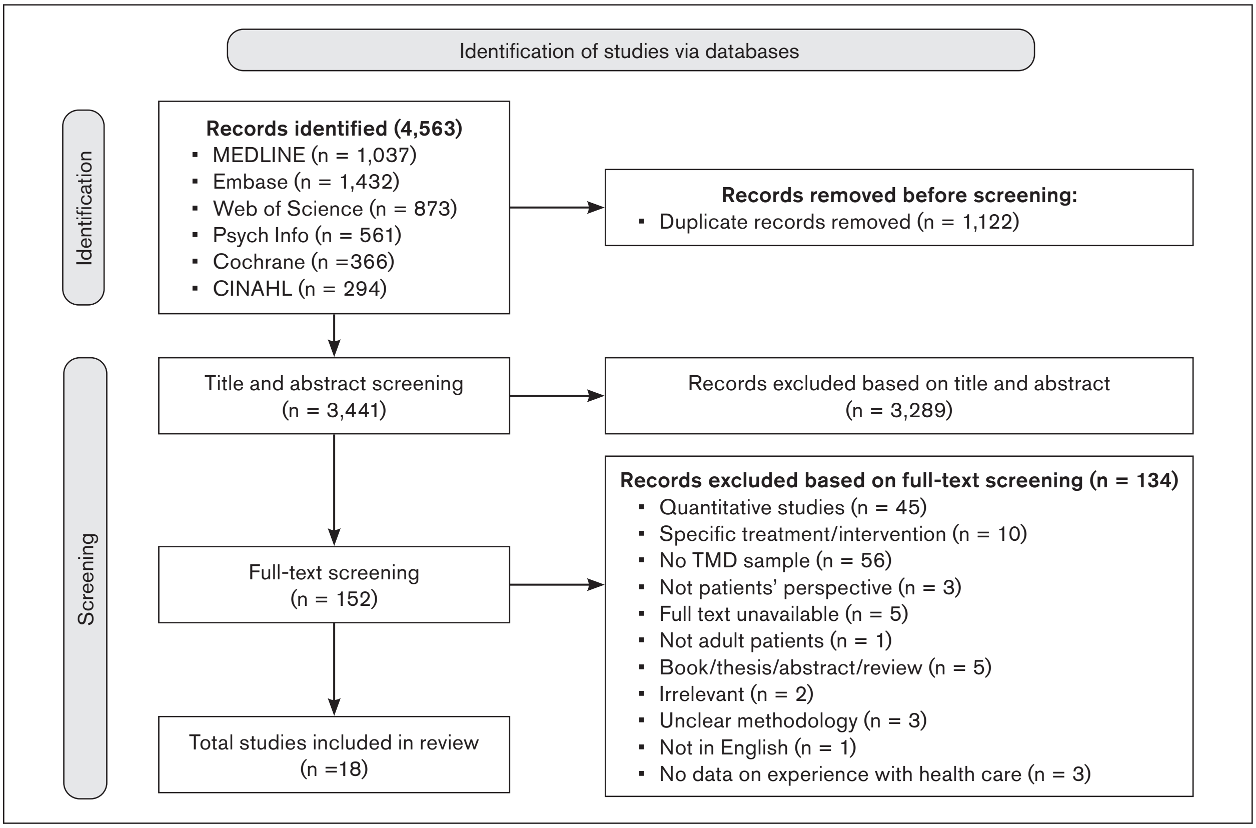

Fig 1 Flowchart of the study selection process.

exclusion was not set.[18,20] Such a 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 (D.T. and R.N.R.) independently appraised the included studies and then discussed the results together.

Data Extraction and Synthesis

The content of the studies was extracted by two reviewers (D.T. and R.N.R.). The data extracted included objectives, participant demographics, criteria for diagnosis of TMDs, method of data collection, and method of analysis.

Further data extraction and synthesis followed the thematic synthesis approach developed by Thomas and Harden.[21] This approach involves line-by-line coding of the data from the primary studies and then organization of 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 the 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 categorizing them to produce statements representing that aggregation. These categories were then used to produce a set of synthesized findings. The themes were derived using an inductive iterative process, where the identified concepts were applied to subsequent studies but new ones were 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 then applied. 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 (ID: CRD42020176820) and reported according to the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) statement.[23]

Results

Description of Studies

The search based on the proposed strategies yielded 4,563 articles across all databases. A total of 3,441 articles remained after removal of duplicates. After the selection step, 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 shows a flowchart of the selection process.

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 and Hovey (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 (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; Q1 = clear aims; Q2 = appropriate methodology; Q3 = appropriate research design; Q4 = appropriate recruitment strategy; Q5 = data collection; Q6 = consideration of relationship between researcher and participants; Q7 = ethical isses; Q8 = rigorous data analysis; Q9 = clear statement of findings; Q10 = value of the research.

Two author groups published two papers each from the same population, as demonstrated by the identical sample size and distribution of men and women. All four papers were included in the review, as the focuses of these papers were different. Garro et al[38] and Wolf et al[37] reported extensively on patient experiences with health care, while Garro et al[30] and Wolf et al[36] explored the experiences with TMDs and the effect on daily life while still containing data relevant to the present 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.

Care-Seeking Attitudes

The first theme describes the factors that drove TMD patients to seek medical help and their concerns regarding health care services.

Need for information.

Patients looked for information online and from friends, textbooks, and magazines.[24–27] However, the information received from 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 about people believing they were exaggerating the symptoms.[9,24,29,36] They therefore turned to health care professionals to seek validation and legitimization of their symptoms, as this entitled them to seek support and helped ease some of the anxiety.[28,30,39] Patients also considered this 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.*[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.*[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.*[39]

Patient characteristics.

Some patients were more insistent than others on getting professional help. Personal traits, such as catastrophizing, may dictate this desire. 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 help 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 tumor, maybe something is wrong.*[26]

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

Nature of symptoms.

Persistent or recent changes 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 health care services[8,26]:

> *I am very close to actually going back now [to 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.*[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.*[39]

Concerns seeking health care.

Some of the concerns that 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 covering TMDs in some countries.[38] And the more clinicians they saw, the more concerned they were about the cost.[25,30,32,38] Additionally, patients 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.*[31]
>
> *Taking time off is too much hassle.*[26]

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

Expectations and Health Care Experience

The second theme describes the general experiences of TMD patients within health care, for which 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 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 these services could help patients move forward 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 with health care services as ambiguous and felt passed around and unsupported, especially in primary care.[9,29,34,37,39] They also reported inadequate clinical discussions about their condition, difficulties with 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 specialties, such as ear-nose-throat, oral surgery, and psychology, as well as 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, leading to incomplete management, prolonged recovery, and exacerbated concerns[9,33,39]:

> *Well, I felt terrible, especially when my GP refused to refer me anywhere and told me I was a time waster who was just imagining it. And, you know, not to bother him anymore.*[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*

Table 2 Details of Included Articles

Study	Country	Aim(s)	Sample size, n	Age, y	Sex distribution, n
Durham et al (2010)[33]	UK	To describe the difficulties that sufferers of TMDs encounter obtaining a definitive diagnosis of their condition and to critically examine the impact of these difficulties	19	18–60	14 F, 5 M
Mienna et al (2014)[35]	Sweden (Arctic Circle)	To explore thoughts, experiences, and beliefs regarding TMDs among Sami women with and without TMDs in order to gain insight into their health care experiences and to generate a hypothesis regarding factors associated with long-standing TMDs.	17 (10 with TMDs + 7 healthy controls)	23–58	All F
Bonathan et al (2014)[24]	UK	To explore patients' understanding of their orofacial pain.	12	26–73	9 F, 3 M
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 COFP symptoms and their treatment-seeking behavior.	25	65–83	21 F, 4 M
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	12 F, 4 M
Peters et al (2015)[34]	UK	To understand patients', GPs', and dentists' experiences of COFP and to identify what barriers may exist to improving psychologic management within dental and medical services.	7	17–56	5 F, 2 M
Breckons et al (2017)[8]	UK	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 concurrent to this substudy	22 (18 for a second interview)	< 40 to > 70	17 F, 5 M
Hazaveh and Hovey (2018)[29]	Canada	To explore 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	1 M, 5 F
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(s).	300 (140 randomly selected 3Q-positive patients and 160 age- and gender-matched 3Q-negativcco-ntrols)	20–69	201 F, 99 M
Nilsson et al (2016)[31]	Sweden	To explore adolescents' explanations of their TMD pain, their pain management strategies for TMD pain, and their treatmentseeking behavior.	21	15–19 (mean 17.2)	19 F, 2 M
Durham et al (2011)[9]	UK	To develop a robust, empirically derived map of TMD sufferers' journey through care.	29	18–65	23 F, 6 M

Table 2 Details of Included Articles (*continued*)

Study	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Durham et al (2010) [33]	TMDs (suffering from pain [ie, myofascial pain and arthritides] and those suffering from mechanical dysfunction due to disc displacement)	RDC/TMD	Specialist oral and maxillofacial surgery and restorative dentistry clinics	Semi-structured individual interviews.	Constant comparative method. Line-by-line coding inductive and iterative to develop theory.
Mienna et al (2014) [35]	TMDs	RDC/TMD	–	Individual interviews.	Grounded theory.
Bonathan et al (2014) [24]	COFP of nondental origin (including TMDs)	–	Orofacial pain clinic	Individual semi-structured interviews (face to face and telephone) + narrative letter.	Thematic analysis.
Au et al (2014) [25]	Nondental orofacial pain (including TMDs)	–	Attendees at daytime social and community centers	Semi-structured individual interviews.	Thematic framework approach that involved a multi-stage thematic analysis.
Rollman et al (2013) [26]	TMDs	–	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]	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]	Persistent orofacial pain of nondental origin (including TMDs)	–	–	Telephone/ face-to-face semi-structured interviews.	Iterative thematic analysis.
Hazaveh and Hovey (2018) [29]	Orofacial pain of nondental origin (including jaw pain)	–	Pain clinic	In-depth individual interviews.	Phenomenologic approach based on the reading approaches.
Fjellman-Wiklund et al (2019) [28]	TMDs	RDC/TMD	Public Dental Health Service	Written questionnaire.	Qualitative content analysis (manifest interpretations).
Nilsson et al (2016) [31]	TMDs	RDC/TMD	Orofacial pain clinic	Semi-structured individual interviews.	Qualitative manifest content analysis with an inductive approach.
Durham et al (2011) [9]	TMDs	Diagnosis by criteria derived from the RDC/TMD	Dental hospital	Semi-structured individual interviews.	Constant comparative method and thematic analysis.

Table 2 Details of Included Articles (*continued*)

Study	Country	Aim(s)	Sample size, n	Age, y	Sex distribution, n
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	–
Wolf et al (2006) [37]	Sweden	To use a qualitative research study to analyze the experiences of patients with nonspecific COFP with respect to consultations for their pain condition.	14	21–77	11 F, 3 M
Wolf et al (2008) [36]	Sweden	To analyze the nonspecific COFP patient's experience of the pain condition and to gain knowledge on the complexity of the problem.	14	21–77	11 F, 3 M
Garro et al (1994) [38]	US	To provide, 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	27 F, 5 M
Garro (1994) [30]	US	Aims not clear.	32	23–69	27 F, 5 M
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	8 F, 1 M
Dinsdale et al (2022)[39]	Australia	This study aimed to qualitatively investigate *(1)* the experience of individuals seeking professional care for persistent intra-articular TMDs and *(2)* key management needs and preferences of this population.	13	22–61 (mean 32.7)	12 F, 1 M

> *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.*[32]
>
> *An adequate interview was missing, no good questions.*[26]

Patient 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 preconceived 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.*[24]

Pleasant experiences.

Other patients, however, were content with their experiences in health care. They discussed the benefits of the clinical visit in reducing their worry, positively impacting their relationship with the pain, 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.*[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.*[24]

Frequent clinical attendance.

Another subtheme that emerged was the repeated clinical attendance for patients with TMDs.[9,26,30,33,38]

Table 2 Details of Included Articles (*continued*)

Study	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Eaves et al (2015) [32]	TMDs	RDC/TMD	Community outreach and newspaper advertisements	Open-ended, semi-structured interviews.	Not stated—interviews were transcribed verbatim and coded. Basic code structure consisted of a set of themes.
Wolf et al (2006) [37]	Nonspecific COFP (including jaw pain/TMD)	RDC/TMD	Orofacial pain unit	Individual thematic in-depth interviews.	Qualitative phenomenologic approach.
Wolf et al (2008) [36]	Nonspecific COFP (including jaw pain/TMDs)	RDC/TMD	Orofacial pain unit	Individual thematic in-depth interviews.	Qualitative research strategy based on phenomenology.
Garro et al (1994) [38]	TMDs	Self-report	"TMJ" support groups	Open-ended, semi-structured interviews.	Not stated—a framework of events and themes was filled out during the interviews.
Garro (1994) [30]	TMDs	Self-report	Support group members	Open-ended, semi-structured interviews.	Not stated—interviews were taped and transcribed, and the content was analyzed with recurring themes noted.
Ilgunas et al (2020) [27]	GJH and TMDs	Beighton score for hypermobility, none for TMD	Department of Clinical Oral Physiology	Semi-structured individual interviews.	Qualitative content analysis and inductive approach.
Dinsdale et al (2022)[39]	Intra-articular TMDs	DC/TMD	Flyers placed in community-based clinic waiting rooms + social media advertisement (Facebook)	Semi-structured interviews conducted 1:1 via Zoom.	Essentialist thematic approach.

3Q/TMD = three mandatory screening questions; GHJ = general joint hypermobility.

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 TMDs, unresolved pain, dissatisfaction with the clinical visit, and the low self-efficacy and need for ongoing care in some patients. 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 were taking the whole situation very seriously.*[8]

Patient-Clinician Interaction

The third theme describes the possible impact of health care professionals 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.*[39]

Support and empathy.

"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 given a thorough examination. This consequently encouraged trust in the information and diagnosis offered, even if scans and tests were expected. The patients trusted the proposed treatment and felt more able to self-manage[8,9,24]:

Table 3 CERQual GRADE Evidence Profile for Review Findings

Summary of review finding	No. of studies contributing to finding (ref no.)	Methodologic 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[28])	No or very minor concerns.	No or very minor concerns.	Minor concerns (2 studies had a TMD sample in addition to other COFP conditions,[24,25] 1 of which consisted of elderly patients[25]).	High confidence
2. Validation of the pain experience: This 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[28,30])	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[24,29]).	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[26]).	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[8,26,39]).	No or very minor concerns (1 study had a TMD sample in addition to other COFP conditions[8]).	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[30,32])	No or very minor concerns.	No or very minor concerns.	Minor concerns (1 study had a TMD sample in addition to other COFP conditions and consisted mainly of elderly patients,[25] and 1 study consisted of adolescent patients[31]).	High confidence
6. Patients were unhappy with the health care 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[32])	No or very minor concerns.	No or very minor concerns.	Minor concerns (3 studies had a TMD sample in addition to other COFP conditions,[8,29,34] and 1 consisted of adolescent patients).	High confidence
7. Patients who were content with the clinical visit reported reduced anxiety and a 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 study had a TMD sample in addition to other COFP conditions[24]).	Moderate confidence
8. Repeated clinical attendance to health care 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 has low CASP[30])	No or minor concerns.	No or very minor concerns.	No or very minor concerns.	High confidence
9. The patient-clinician interaction: A negative attitude on the part of the clinician was sometimes reported. This 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 has low CASP[30])	No or minor concerns.	No or very minor concerns.	Moderate concerns (5 studies had a TMD sample in addition to other COFP conditions,[8,24,29,34,37] 1 consisted of elderly patients,[25] and 1 consisted of Sami women[35]).	High confidence

Table 3 CERQual GRADE Evidence Profile for Review Findings (*continued*)

10. The patient-clinician interaction: Understanding and empathic clinicians inspired 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 need to be explored more thoroughly).	Minor (2 studies had a TMD sample in addition to other COFP conditions[8,24]).	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[30,32])	No or very minor concerns.	No or very minor concerns.	No or very minor concerns (1 study had a TMD sample in addition to other COFP conditions[24]).	High confidence
12. Management: A range of treatment options were offered with varying degrees of success. They were occasionally inconsistent or inappropriate, which led to ineffective pain control.	9 studies (8, 28–33, 35, 38)	Minor concerns (3 of the 9 studies have low CASP[28,30,32])	No or very minor concerns.	No or very minor concerns.	Moderate concerns (2 studies had a TMD sample in addition to other COFP conditions, 1 of which consisted of Sami women[35] and 1 that consisted of adolescent patients[31]).	High confidence
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 had a TMD sample in addition to other COFP conditions[24]).	High confidence
14. Family and friends: While some patients relied heavily on the support of family and friends to cope with the pain, others preferred to deal with the pain on their own. They did not want to burden family and friends with their pain or assume the identity of a chronic pain patient.	5 studies (25, 27, 29, 31, 32)	Minor concerns (1 of the 5 studies has low CASP[32])	No or very minor concerns.	No or very minor concerns.	Moderate concerns (2 studies had a TMD sample in addition to other COFP conditions,[25,29] 1 of which consisted of elderly patients.[25] Another consisted of adolescent patients[31]).	High confidence

> *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.*[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.*[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.*[9]

Skepticism.

Negative experiences were also described. Patients reported facing skepticism about the authenticity and severity of the complaints, disinterest, or the implication that they were imagining their pain and seeking attention. They also reported limited time given discussing the problem and a 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 and discouraged them from seeking further treatment.[24,25,27] Interestingly, this was also reported by some patients with symptoms of hypermobility and 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.*[8]

Diagnosis as a Stepping Stone for Improvement

The fourth theme describes the importance of receiving a diagnosis for patients with TMDs. 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 signaling 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 their own explanations for 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 tumor?" etc, etc.*[8]
> *I got panic-stricken. I didn't know what was going on.*[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.*[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 their complaints, acknowledged their illness, and confirmed they were "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.*[33]

> *It also meant receiving the right information about the condition and initiating discussions about the treatment options. Hence, diagnosis 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.*[33]

Management

The fifth theme describes the different management strategies offered to 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 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 painkillers.[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].*[33]

On occasion, treatment plans consisted of multiple attempts until the effective modality was found.[8] A range of management approaches were offered to treat TMDs 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 and 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 their ability to self-manage was associated with their knowledge of the illness, the triggers, its fluctuating course, confidence in the clinician, and reduction in pain and dysfunction levels so that they were able to manage these 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.*[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]

Social Support

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

Support groups.

Social networks were reportedly important for patients with TMDs. They welcomed being informed of support groups, as it confirmed that they were not alone. They appreciated the knowledge shared and it 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.*[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] while 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.*[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.*[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 the present authors' knowledge, this is the first qualitative systematic review focusing on the experiences of TMD patients within health care services. In the quality appraisal of the included studies with 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 such studies should not be viewed in the same light as quantitative research. It is argued that the basic epistemologic and ontologic 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 some studies may be more rigorous and well conducted than others. Therefore, quality should be subject to critical appraisal.[43] The Cochrane Guidelines currently state that the assessment of methodologic 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 present review. Interestingly, most of the papers did not discuss the influence of the interviewer on the participants (item 6 of CASP checklist), 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 nonmalignant musculoskeletal pain,[49,50] and low back pain.[51] Strong similarities in findings were identified, which suggests that despite the localized nature of TMDs, they 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 for patients, which is not only expected, but also humane.[52] Previous reviews of chronic pain conditions have revealed an element of dissatisfaction with health care 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 health care 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.[34,56] This is likely due to insufficient exposure to TMD problems in their undergraduate studies or lack of the skillset necessary to manage patients with TMDs during subsequent postgraduate training.[34] Regardless of the cause of the hesitation in the diagnosis and management of patients with TMDs in primary care, this can lead to onward referral to more than one specialist service; hence, the "shuttlecock" experience. The participants in this review did not highlight a distinction between GPs and dentists as first point of contact or any effect this might have had on the overall clinical experience. However, in their qualitative study of dentists, GPs, and patients, Peters et al noted that GPs felt responsible for these patients and tried to avoid "yo-yo-ing" them between dental and medical services. GPs were also more open to using psychologic approaches to management.[34] Aggarwal et al also reported in their study that 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 United States, dentistry and medicine have separate systems in terms of practice and financing arrangements.[58] Both types of practitioner are more likely to focus on the symptoms of TMDs that fall within their area of training, and it usually falls to the patients to navigate and coordinate between multiple health care professionals.[58]

The importance of receiving a diagnosis was highlighted strongly in this review. This has been 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 for 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] However, some misconceptions are commonly associated with chronic pain, such as the necessity of imaging to diagnose pain conditions and the belief that activities should be avoided when in pain.[60,61] Therefore, effective discussion about patient expectations, fears, and beliefs is encouraged, as this may work to empower patients, alleviate their concerns, and allow them to develop the skills essential for managing their pain and decreasing dependency on health care professionals.[59] Different modes can be utilized to deliver education, such as verbal discussions, written material (leaflets and pamphlets), and audiovisual 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, and coping techniques, as well as 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 patients and are integral to their ability to self-manage.[55] TMD patients felt strongly about the importance of being looked after by an understanding and empathic clinician. This might make them more receptive to information and more able to cope with their symptoms. In their systematic review, Doyle et al also reported 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 TMDs.[9] A potential application of this map is to identify the time points in clinical care where introducing intervention would be most useful. These authors suggest that the life effects of TMD could be reduced if standardized conservative therapy is introduced early in primary care alongside early diagnosis. This helps establish perceived control over the condition and could also aid in decreasing the burden on secondary care in terms of managing these patients.[9]

Multiple studies have explored the barriers to health care in different countries.[64–67] Some of the factors revealed parallel the present results, such as unfavorable evaluation of medical care, some personality traits, and traditional barriers, such as access, time, and cost of care. These shared barriers confirm that such health care problems are not exclusive to COFP patients but span different fields and different countries. These results suggest that long waiting times to get an appointment or a referral might inflame patients' anxiety, worsen their symptoms, and possibly make them more prone to self-constructed explanations for 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 relevant studies were included, as the focus was on articles published in the English language in the six aforementioned databases. Gray literature was also not included, which may have introduced some publication bias.

A sensitivity analysis to assess whether exclusion of the studies with lower CASP outcomes might have changed the results was not formally conducted. 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 underrepresented, and caution is advised when applying these findings to all TMD patients. It is also worth mentioning that only a minority of patients with signs and symptoms of TMDs present for treatment.[2]

The synthesis of qualitative evidence 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, the authors 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 decontextualize the findings of the primary studies.[21,69] The present authors attempted to preserve context in this review by presenting a summary of each primary study so that the readers can judge the transferability of the findings to their own setting.

Conclusions

The effects of TMDs on patients' lives range from minimal to debilitating. In consequence, patients may become anxious, depressed, and/or melancholic. Thus, when these effects are combined with the problems within health care, especially primary care, an unpleasant encounter could arise for both parties. Ongoing research has already identified some problems within the pathway of health care for COFP patients and suggests that the current pathway does not meet patient needs. Further research is needed to determine the parts of health care experience that have the most potential effect on patient-reported outcomes and to quantify these effects in order to maximize the effectiveness of financial resources in correcting these problems.

Highlights

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

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Appendix 1 Search Strategy in MEDLINE, Embase, and PsychInfo

1. Temporomandibular Joint Disorders/
2. Temporomandibular Joint Dysfunction Syndrome/
3. Facial Pain/
4. Temporomandibular Joint/
5. Temporomandibular Joint Disc/
6. Masticatory Muscles/
7. Myalgia/
8. Arthralgia/
9. 6 and 7
10. 4 and 8
11. (TMD or TMJD or Temporomandibular disorder* or Temporomandibular joint dysfunction* or internal joint derangement* or Disc displacement or Fac* myalgia or masticat* muscle pain* or Degenerative joint disease or luxation* or orofac* pain* or Cranio* pain* or Fac* arthromyalgia or fac* pain).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
12. Personal Satisfaction/
13. ”Quality of Life”/
14. Social Support/
15. Depression/
16. Anxiety/
17. Attitude/
18. (Experience* or Satisfaction* or Cop* or Support* or Stress* or resilience or quality of life or healthcare service* or health care service* or perspective* or concern* or opinion*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
19. Qualitative Research/
20. Focus Groups/
21. Interview/
22. Grounded Theory/
23. (qualitative stud* or qualitative research or interview* or discussion* or audio recording* or constant comparative analysis or content analysis or ethnograph* or field note* or field stud* or focus group* or grounded theor* or narrative* or observation or them* analysis or diary study).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
24. 12 or 13 or 14 or 15 or 16 or 17 or 18
25. 19 or 20 or 21 or 22 or 23
26. 1 or 2 or 3 or 4 or 5 or 9 or 10 or 11
27. 24 and 25 and 26
28. limit 27 to (human and english language)

Appendix 2 Search Strategy in Cochrane Database

ID	Search	Hits
#1	MeSH descriptor: [Temporomandibular Joint Disorders] explode all trees	
#2	MeSH descriptor: [Temporomandibular Joint Dysfunction Syndrome] explode all trees	
#3	MeSH descriptor: [Facial Pain] explode all trees	
#4	MeSH descriptor: [Temporomandibular Joint] explode all trees	
#5	MeSH descriptor: [Masticatory Muscles] this term only	
#6	MeSH descriptor: [Myalgia] explode all trees	
#7	MeSH descriptor: [Arthralgia] this term only	
#8	#4 and #7	
#9	#5 and #6	
#10	TMD or TMJD or ”Temporomandibular disorder*” or ”Temporomandibular joint dysfunction*” or ”internal joint derangement*” or ”Disc displacement” or ”Fac* myalgia” or ”masticat* muscle pain*” or ”Degenerative joint disease” or luxation* or ”orofac* pain*” or ”Cranio* pain*” or ”Fac* arthromyalgia” or ”fac* pain”	
#11	#1 or #2 or #3 or #8 or #9 or #10	
#12	MeSH descriptor: [Quality of Life] explode all trees	
#13	MeSH descriptor: [Social Support] explode all trees	
#14	MeSH descriptor: [Depression] explode all trees	
#15	MeSH descriptor: [Anxiety] explode all trees	
#16	MeSH descriptor: [Attitude] this term only	
#17	Experience* or Satisfaction* or Cop* or Support* or Stress* or resilience or ”quality of life” or ”healthcare service*” or ”health care service*” or perspective* or concern* or opinion*	
#18	#12 or #13 or #14 or #15 or #16 or #17	
#19	MeSH descriptor: [Qualitative Research] explode all trees	
#20	MeSH descriptor: [Focus Groups] explode all trees	
#21	MeSH descriptor: [Interview] explode all trees	
#22	MeSH descriptor: [Grounded Theory] explode all trees	
#23	”qualitative stud*” or ”qualitative research” or interview* or discussion* or ”audio recording*” or ”constant comparative analysis” or ”content analysis” or ethnograph* or ”field note*” or ”field stud*” or ”focus group*” or ”grounded theor*” or narrative* or observation or ”them* analysis” or ”diary stud*”	
#24	#19 or #20 or #21 or #22 or #23	
#25	#11 and #18 and #24	

Appendix 3 Search Strategy in CINAHL Plus

S48	S34 AND S40 AND S47 (Limiters - English Language; Exclude MEDLINE records)
S47	S41 OR S42 OR S43 OR S44 OR S45 OR S46
S46	”qualitative stud*” or ”qualitative research” or interview* or discussion* or ”audio recording*” or ”constant comparative analysis” or ”content analysis” or ethnograph* or ”field note*” or ”field stud*” or ”focus group*” or ”grounded theor*” or narrative* or observation or ”them* analysis” or ”diary stud*”
S45	(MH ”Thematic Analysis”)
S44	(MH ”Grounded Theory”)
S43	(MH ”Semi-Structured Interview”) OR (MH ”Unstructured Interview”) OR (MH ”Structured Interview”) OR (MH ”Interviews”)
S42	(MH ”Focus Groups”)
S41	(MH ”Qualitative Studies”)
S40	S35 OR S36 OR S37 OR S38 OR S39
S39	Experience* or Satisfaction* or Cop* or Support* or Stress* or resilience or ”quality of life” or ”healthcare service*” or ”health care service*” or perspective* or concern* or opinion* or ”attitude*”
S38	(MH ”Anxiety”)
S37	(MH ”Depression”)
S36	(MH ”Quality of Life”)
S35	(MH ”Personal Satisfaction”)
S34	S25 OR S26 OR S29 OR S32 OR S33
S33	TMD or TMJD or ”Temporomandibular disorder*” or ”Temporomandibular joint dysfunction*” or ”internal joint derangement*” or ”Disc displacement” or ”Fac* myalgia” or ”masticat* muscle pain*” or ”Degenerative joint disease” or luxation* or ”orofac* pain*” or ”Cranio* pain*” or ”Fac* arthromyalgia” or ”fac* pain”
S32	S30 AND S31
S31	(MH ”Arthralgia”)
S30	(MH ”Temporomandibular Joint”)
S29	S27 AND S28
S28	(MH ”Muscle Pain”)
S27	(MH ”Masticatory Muscles”)
S26	(MH ”Facial Pain”)
S25	(MH ”Temporomandibular Joint Diseases”) OR (MH ”Temporomandibular Joint Syndrome”)

Appendix 4 Search Strategy in Web of Science

# 4	(#3 AND #2 AND #1) AND LANGUAGE: (English)
# 3	TS=(Experience* or Satisfaction* or Cop* or Support* or Stress* or resilience or ”quality of life” or ”healthcare service*” or ”health care service*” or perspective* or concern* or opinion* or depress* or anxi*)
# 2	TS=(”qualitative stud*” or ”qualitative research” or interview* or discussion* or ”audio recording*” or ”constant comparative analysis” or ”content analysis” or ethnograph* or ”field note*” or ”field stud*” or ”focus group*” or ”grounded theor*” or narrative* or observation or ”them* analysis” or ”diary stud*”)
# 1	TS=(”Temporomandibular Joint Disorders” or ”Temporomandibular Joint Dysfunction Syndrome” or TMD or TMJD or ”Temporomandibular disorder*” or ”Temporomandibular joint dysfunction*” or ”internal joint derangement*” or ”Disc displacement” or ”Fac* myalgia” or ”masticat* muscle pain*” or ”Degenerative joint disease” or luxation* or ”orofac* pain*” or ”Cranio* pain*” or ”Fac* arthromyalgia” or ”fac* pain”)