

REVIEW ARTICLE

A meta-synthesis of qualitative data exploring the experience of living with temporomandibular disorders: The patients' voice

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Abstract

Objective: The aim of this review was to systematically review the qualitative evidence related to the experience of patients with temporomandibular disorder (TMD) and to explore the effect it has on their lives.

Materials and methods: The following databases were searched systemically: Medline, Embase, PsycINFO, Web of Science, CINAHL Complete and the Cochrane database. Thematic synthesis was used to analyse and synthesise the data from the qualitative studies which explored the experience of adult patients with TMD. The Critical Appraisal Skills Programme (CASP) tool was used to critically appraise the quality of the included studies.

Results: The search strategies yielded 3588 articles across all databases. A total of 20 articles were eventually included. Six themes were derived: TMD causes uncertainty and doubt, TMD had disruptive effects on life, TMD causes distress, understanding TMD—the illness and the causes, dealing with the pain and aims and hopes.

Conclusion: The findings highlight the impact TMD could have on the quality of life and confirms the psychological and social challenges these patients experience.

KEYWORDS

facial pain, qualitative evidence synthesis, TMJ

1 | INTRODUCTION

Temporomandibular disorder (TMD) refers to a group of conditions that affect the temporomandibular joint and surrounding muscles.¹ Patients often report symptoms of pain in the jaw area and surrounding musculature, clicking sounds, alterations to the joint activities such as: deviation in the arc of movement, limitation to mouth opening, headache and earache.^{2,3} TMD represents the most common cause of chronic pain in the orofacial region,⁴ and is only behind headache and backache as reason for chronic pain in general.⁵

Accepting the nature of chronic pain can be difficult for patients, therefore creating challenges to their daily lives.⁶ Simple physical activities could become burdensome, and

social interactions with family and friends may become more difficult. Chronic pain is also linked with depression, which may go unrecognised and therefore untreated in such patients.^{7,8} It is likely that the relationship is bidirectional, with chronic pain thought to contribute and also result in poor mental health.⁹ Similarly with anxiety and fear of pain, which are both linked to increased likelihood of chronic pain and poorer recovery should it develop.¹⁰ It is therefore important for clinicians to be aware of the influence of chronic pain on patients and address the modifiable risk factors such as lifestyle and behaviour to reduce the impact it has on their lives.¹¹

The aim of this review was to synthesise the available qualitative evidence about the experience of living with TMD and the effects it has on daily life. Qualitative evidence

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synthesis offers richer insight than individual primary qualitative studies as it integrates the research findings on this topic in one place.¹² It helps improve our understanding of pain as recounted by the patients themselves, and therefore helps improve the quality of care offered to such patients.¹³

A thematic synthesis approach was utilised in this systematic review. Thematic synthesis is one of the range of methods available to synthesise qualitative data. It was chosen as it allows the identification of the prominent themes and organises the identified literature under these themes in a flexible way.¹⁴

2 | MATERIALS AND METHODS

This review was registered on PROSPERO with the following ID: CRD42020171854. It was reported according to The Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement.¹⁵

2.1 | Search strategy and locating the literature

The premise of the search strategy was based on the acronym SPICE which represents the following: Setting: social setting, Perspective: patients, Phenomenon of Interest: temporomandibular disorders, Comparison: none, Evaluation: effect on life. This acronym, developed by Booth,¹⁶ is a qualitative counterpart to PICO which is frequently used in quantitative systematic reviews. The key words were first identified by running an initial search in Medline and Embase. The following MeSH terms and key words were used: (Temporomandibular Joint Disorders or Temporomandibular Joint Dysfunction Syndrome or Facial Pain or Fac* myalgia or masticat* muscle pain*) AND (Personal Satisfaction or Social Support or Anxiety or Depression or Attitude or Experience* or Satisfaction* or Cop*) AND (Qualitative research or Interview or Focus groups or qualitative stud* discussion* or audio recording*).

The search strategy aimed to locate all available articles and was constructed for each database in collaboration with a clinical librarian. The search was conducted on 25 June 2021, and the data bases used were Medline, Embase, PsycINFO, Web of Science, CINAHL Complete and the Cochrane database. After identifying the eligible articles, the reference lists were hand searched to identify any articles missed from the original search.

The articles eligible for selection were qualitative studies exploring the experience of adult (>16) patients with TMD and jaw pain. Mixed methods studies were included if the qualitative section was clearly separate from the quantitative section, and only qualitative data were included. Studies with a sample of mixed chronic orofacial pain conditions (COFPs) were included if they contained a sample of TMD patients. The findings and quotes attributed to TMD patients were included, in addition to the data which was not assigned to a particular pain condition. The rationale for this approach, was that these findings applied to the various orofacial pain

conditions under investigation in the studies, including TMD. The findings and quotes which were assigned to another pain condition, such as Trigeminal Neuralgia or Oral Dysaesthesia, were not included in 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. Studies were excluded if they were not in the English language, if they reported on the experience with a certain treatment or intervention and if the full text was unavailable.

2.2 | Study selection and critical appraisal

The studies yielded from the search strategy were reviewed by two reviewers independently (DT and RNR). The selection process started with reviewing the title and abstract. The articles which potentially met the inclusion criteria and those which did not contain enough information in the abstract moved to the next step of full article review. The final studies were selected after several discussions among the research team.

The studies included in the review were appraised to assess the transparency of research practice and reporting standards using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist. This tool was used as it allows for the appraisal of all types of qualitative studies and is the most commonly used tool for qualitative evidence syntheses in Cochrane and World Health Organisation (WHO) guideline processes.¹⁷ It consists of 10 questions with 'Yes', 'No' and 'Cannot tell' as possible answers. Two reviewers independently reviewed the studies (DT and RNR) and discussed the results jointly.

2.3 | Data extraction and synthesis

The context of each study was extracted by two reviewers (DT and RNR). The data included: aims of the study, country, 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. This method was developed by Thomas and Harden¹⁸ and involves several steps. First of which is line-by-line coding of the data found under 'findings' or 'results' of the primary studies according to its meaning and content. The codes were examined for similarities and differences and were then organised into 'descriptive themes'. Each descriptive theme contained the codes which were related to each other and feed into that specific theme. Up to this point, the themes reflected the meaning portrayed by the primary studies. Following that, analytical themes were derived. This step is where the analysis 'goes beyond' the content of the original studies, to generate additional concepts and understandings. This step of 'going beyond' the original studies is the defining characteristic of thematic synthesis.^{19,20} The derivation of themes

was an inductive and iterative process, where later studies were analysed using concepts generated in earlier studies. However, new concepts were created when necessary.

Following data synthesis, the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach was employed to assess the confidence in the findings. Confidence in the findings of qualitative research is 'an assessment of the extent to which a review finding is a reasonable representation of the phenomenon of interest'.²¹ It considers four components: methodological limitations, coherence, adequacy of data and relevance.²²⁻²⁵

3 | RESULTS

The search based on the proposed strategies yielded 3964 articles across all databases. 2344 articles remained after removing the duplicates. After the first step of selection, which involved screening of the titles and abstracts, 140 papers were included for full text review. Following full text review, 20 studies were finally selected to be included in the qualitative evidence synthesis.²⁶⁻⁴⁵ See [Table 1](#) for the context of the included studies, [Table 2](#) for the CASP quality appraisal, and [Table 3](#) for the GRADE-CERQual evidence profile. No studies were excluded based on their quality.

4 | FINDINGS AND THEMES

4.1 | TMD causes uncertainty and doubt

This theme describes the feelings of uncertainty and self-doubt that arose prior to receiving a diagnosis. These feelings arose soon after experiencing the first symptoms and were sometimes further compounded even after seeking professional help.²⁶ Worry was due to the mystery of the cause and not having an explanation to the symptoms.²⁷⁻²⁹ Clinical interactions did not necessarily reduce the uncertainty, as some patients faced scepticism or partial explanations from healthcare professionals. This fed into the circle of emotional distress and reportedly exacerbated symptoms.^{26,30}

"I got to the point where because I'd complained about it so much I just stopped complaining because...no-one seems to know what's wrong. So you think oh maybe it's just me, you know, psychosomatic." (Sufferer 3-TMD).²⁶

Further uncertainty arose in anticipation of future flare ups, fear of symptoms worsening over time or of the jaw 'wearing down' causing irreversible damage.³¹

"I'll often think, 'I should chew this the right way', or not use that side of my mouth. That's always in the back of my mind" – 001.³¹

4.1.1 | Self-constructed explanations to rationalise the symptoms

Constructing explanations to try to understand the pain were also reported.^{26,28,30,32} On occasions, these explanations turned into firmly held theories that led to confusion and rejection of information if they were not in line with their preconceptions.²⁸

"It preyed on my mind...because I did have a big pain, you know...the girl I worked with she's got a brain tumour ... she's had it about five years now. She had headaches for a long time... You know, it sounds really hard, but you think." (Sufferer 9-TMD).²⁶

4.1.2 | Desire to make the pain visible

Patients expressed a strong desire to make the pain visible, to provide proof of their symptoms and confirm the reality of their pain.²⁸ The invisibility of pain undermined the complaints for some patients.^{33,34} Consequently, this drove them to take matters into their own hands by insisting on being taken seriously and demanding specific treatments or referrals.³⁵

"Sometimes it's so frustrating... so frustrating because people can't see that I'm sick. They look at me and they think that I look fine. I don't like it when people think that I'm pretending to be sick." (Interviewee 5-jaw pain).³⁴

"Now [my] last GP visit that I went to, oh, some months ago, I cannot remember when, so obviously I persuaded them to let us take some Voltarol" (Q20, baseline).³⁵

4.1.3 | Self-doubt

Lack of diagnostic certainty caused some patients to question the legitimacy of their symptoms.²⁶ Doubt crept in and they started to wonder whether they were imagining the pain.^{28,35-37} Patients with physical manifestations such as mechanical dysfunction felt that their complaints were legitimate and sought help faster than patients with pain as the only symptom.²⁹

4.2 | TMD has disruptive effects on life

This theme describes the negative ramifications of having to live with TMD. Patients reported effects on their social lives, professional lives, interpersonal relationships and their ability to do day-to-day tasks.

TABLE 1 Context of primary studies

Author	Country	Aim	Sample size	Age	Gender	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Durham et al. ²⁶	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, 5 M	TMD (Suffering from pain, i.e., myofascial pain and arthritides, and those suffering from mechanical dysfunction due to disc displacement	RDC/TMD ^a	Specialist oral and maxillofacial surgery and restorative dentistry clinics	Semi-structured individual interviews	Constant comparative method (Glaser, 1965). Line-by-line coding inductive and iterative to develop theory
Mienna et al. ²⁷	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 healthcare 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. ²⁸	UK	To explore patients' understanding of their orofacial pain	12	26–73	9F, 3 M	COFP ^b 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. ³²	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, 4 M	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. ⁴³	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, 4 M	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

TABLE 1 (Continued)

Author	Country	Aim	Sample size	Age	Gender	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Peters et al. ³⁸	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. ³⁵	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 concurrent to this sub study (Durham et al. 2016)	22 (18 for a second interview)	<40 and >70	17F, 5M	Persistent OFP of non-dental origin (including TMD)	–	–	Telephone/face-to-face semi-structured interviews	Iterative thematic analysis
Hazaveh et al. ³⁴	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	1 M, 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. ⁴⁴	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 3Q-positives, 160 3Q-negatives)	20–69	201F, 99M	TMD	RDC/TMD	Public Dental Health Service	Written questionnaire	Qualitative content analysis (manifest interpretations)
Nilsson et al. ³⁹	Sweden	To acquire a deeper understanding of adolescents' experience of living with temporomandibular disorders (TMD) pain	21	15–19 (Mean age 17.2)	19F, 2 M	TMD	RDC/TMD	Orofacial pain clinic	Semi-structured individual interviews	Manifest and latent content analysis

(Continues)

TABLE 1 (Continued)

Author	Country	Aim	Sample size	Age	Gender	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Nilsson et al. ³⁰	Sweden	To explore adolescents' explanations of their temporomandibular disorder (TMD) pain, their pain management strategies for TMD pain, and their treatment seeking behaviour	21	15–19 (Mean age 17.2)	19F, 2 M	TMD	RDC/TMD	Orofacial pain clinic	Semi-structured individual interviews	Qualitative manifest content analysis with an inductive approach
Durham et al. ²⁹	UK	To develop a robust empirically derived map of TMD sufferers' journey through care	29	18–65	23F, 6 M	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. ⁴⁰	US	Aims not clear	95 did baseline interview/ 44 did four or five interviews (a total of 271 interviews)	18–69	–	TMD	RDC/TMD	Community outreach and newspaper advertisements	Semi-structured, open-ended interviews	Unclear
Wolf et al. ⁴⁵	Sweden	To use a qualitative research study to analyse the experiences of patients with nonspecific chronic orofacial pain with respect to consultations for their pain condition	14	21–77	11F, 3 M	Chronic non-specific OFP (including jaw pain/TMD)	RDC/TMD	Orofacial Pain Unit	Individual thematic in-depth interviews	Qualitative phenomenological approach
Wolf et al. ³³	Sweden	To analyse 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, 3 M	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. ³⁶	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 healthcare system	32	23–69	27F, 5 M	TMD	Self-reporting of the diagnosis of TMD	"TMJ" support groups	Open-ended semi-structured interviews	Unclear

TABLE 1 (Continued)

Author	Country	Aim	Sample size	Age	Gender	Diagnosis	Diagnostic criteria	Recruitment site	Method of data collection	Method of analysis
Garro et al. ³⁷	US	Aims not clear	32	23–69	27F, 5 M	TMD	Self-reporting of the diagnosis of TMD	Support group members	Open ended, semi-structured interviews	Unclear
Safour et al. ⁴¹	Canada	To better understand the experiences of individuals who must alter the types of food they eat because of having a chronic temporomandibular joint disorder (TMD) and the digestive issues that these alterations produce	6	24–46	4F, 2 M	TMD	chronic TMD confirmed by a TMD specialist, and self-reported changes in their dietary habits	Referrals through a university student dental clinic and two general hospitals	Face-to-face open ended, individual semi structured interviews	Interpretive phenomenology
Ilgunas et al. ⁴²	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, 1 M	GJH and TMD	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. ³¹	Australia	To investigate the lived experiences of adults with persistent intra-articular temporomandibular disorders (IA-TMD) by exploring i) the impact of IA-TMD on activity and participation and ii) contextual factors linked with individuals' experiences	16	22–61	14F, 2 M	Intra-articular TMD	DC/TMD, Ohrbach et al., 2013	Privately-owned clinics and social media advertisement	Semi-structures interview framework, using open-ended questions using an online platform (Zoom)	Thematic analysis approach

^aResearch diagnostic criteria for temporomandibular disorders.

TABLE 2 CASP quality appraisal

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Durham et al. ²⁶	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Mienna et al. ²⁷	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Bonathan et al. ²⁸	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Au et al. ³²	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Rollman et al. ⁴³	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Peters et al. ³⁸	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Breckons et al. ³⁵	Yes	Yes	Yes	Yes	Yes	No	Yes	yes	Yes	Valuable
Hazaveh et al. ³⁴	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Valuable
Fjellman-Wiklund et al. ⁴⁴	Yes	Yes	Cannot tell	Cannot tell	Cannot tell	No	Yes	Yes	Yes	Unclear for qualitative part.
Nilsson et al. ³⁹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Nilsson et al. ³⁰	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Valuable
Durham et al. ²⁹	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Eaves et al. ⁴⁰	No	Yes	Cannot tell	Cannot tell	Yes	No	Yes	Cannot tell	Yes	Yes/ somewhat valuable
Wolf et al. ⁴⁵	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Wolf et al. ³³	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Garro et al. ³⁶	Yes	Yes	Yes	Yes	Yes	No	No	Cannot tell	Yes	Yes/ somewhat valuable
Garro et al. ³⁷	No	Yes	No	Yes	Cannot tell	No	No	Cannot tell	Yes	Yes/ somewhat valuable
Safour et al. ⁴¹	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Ilgunas et al. ⁴²	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Valuable
Dinsdale et al. ³¹	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Valuable

4.2.1 | Social interactions

A diminished willingness to participate in social activities was reported. Some patients preferred to be alone when in pain, as they could not cope with being around people. Some also restricted their social interaction for fear of jaw locking in public or embarrassment from joint noises.^{29,31,32,34,36,38-40} The worry of being perceived unreliable when having to frequently cancel plans was also a factor.^{36,37} Additionally, lack of understanding from family members discouraged them from engaging in public activities.²⁹ All of which resulted in feeling isolated and unable to participate in social life.^{26,29,32,33,38,39} They could also be perceived as unfriendly or hostile, as smiling and talking might be painful for some.^{38,40} “I’d be walking down the aisle [at work] and somebody’d say, “Go ahead and smile. It doesn’t hurt.” And I thought about that later and I thought, you know, it does hurt. It hurts to smile.” (Lloyd, 54- TMD).⁴⁰

“On the days I’m in pain, I feel that I can’t do certain things. I can’t cope with being with my

friends because I have a headache.” (P-12, TMD).³⁹

4.2.2 | Personal relationships

Personal relationships with partners were also in jeopardy of being strained.^{29,34,39,40} It might be difficult to articulate the suffering, and a lack of understanding or support might be shown.^{34,40} That also had a toll on intimate relations in some cases, as patients have expressed a reduced sexual desire and pain during kissing.^{31,40} Additionally, some might feel guilt over dragging people around them into their pain, and hence, tried to shelter them from perceived risks.⁴⁰

“It [the pain] stresses you out. You don’t really realise when it does. But I was getting upset with my husband, I was coming in from work and...I was really narky and my husband would get it in the neck.” (Pt 16- Myofascial pain and arthritides group).²⁹

TABLE 3 GRADE-CERQual evidence profile for review findings

Summary of review finding	Studies contributing to review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual overall assessment
1. Uncertainty and doubt: some patients experienced uncertainty prior to seeing a healthcare professional. This was later compounded if the clinical visit was unsuccessful in giving a diagnosis	six studies ^{2,6-31}	Very minor concerns	No or very minor concerns	No or minor concerns	Minor concerns (one study included a TMD sample in addition to other COFP conditions. One study consisted of Sami women only. One study consisted of adolescent patients)	High confidence
2. Self-constructed explanations: some patients tried to rationalise the symptoms by constructing their own explanations. These explanations could turn into firmly held theories	Four studies ^{26,28,30,32}	Very minor concerns	Minor concerns (The pattern of explanations turning into firmly held theories is not explored in detail)	Minor concerns (Explanations turning into firmly held theories is supported in one study)	Moderate concerns (two studies included a TMD sample in addition to other COFP conditions. One of which consisted of elderly people. One study consisted of adolescent patients)	Moderate confidence
3. Desire to make the pain visible: patients expressed a strong desire to make the pain visible in order to confirm the reality of their symptoms. They expressed frustration at the scepticism they faced	Three studies ^{28,33,34}	Very minor concerns	No or very minor concerns	Minor concerns (Not richly explored and supported by three studies only)	Minor concerns (All studies included a TMD sample in addition to other COFP conditions)	High confidence
4. Self-doubt: patients experienced self-doubt when facing diagnostic uncertainty	Five studies ^{2,6,28,35-37}	Minor concerns (one of five studies has low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (two studies include a TMD sample in addition to other COFP conditions)	High confidence
5. TMD affected social interactions: TMD may cause diminished willingness to participate in social activities. Some patients could not cope with being around people when in pain, which resulted in feeling isolated and unable to participate in social life. On the other hand, staying connected to other people helped some patients cope better	Ten studies ^{2,6,29,31-34,36,38-40}	Minor concerns (1 of 10 studies has low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (four studies included a TMD sample in addition to other COFP conditions. One of which consisted of elderly people. One study consisted of adolescent patients)	High confidence
6. TMD affected personal relationships: relationships with partners were sometimes strained due to the difficulty of articulating the suffering and due to a lack of understanding. This had a toll on intimate relations	Five studies ^{29,31,34,39,40}	Minor concerns (One of five studies has low CASP)	Minor concerns (Effects on relationship with partners are not explored in depth and may include additional patterns if explored further)	Minor concerns (Patterns of partner support are not richly explored. Effect on sexual interactions is supported by two studies only)	Minor concerns (One study included a TMD sample in addition to other COFP conditions. One study consisted of adolescent patients)	Moderate confidence

(Continues)

TABLE 3 (Continued)

Summary of review finding	Studies contributing to review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual overall assessment
7. TMD affected professional prospects: maintaining a career was too taxing for some patients. This consequently led to abandonment of jobs on occasions or seeking less demanding ones	Eight studies ^{26,29,31,34-37,40}	Minor concerns (two of eight studies have low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (two studies included a TMD sample in addition to other COFP conditions)	High confidence
8. TMD caused financial strain: in addition to the cost of repeated clinical visits and different treatments, loss of employment led to loss of earnings	Three studies ^{34,36,38}	Very minor concerns	Moderate concerns (This finding is largely tied to the insurance cover and the way the healthcare system works in different countries. Hence this finding may not reflect all patterns)	Minor concerns (Finding supported by three studies only)	Minor concerns (two studies included a TMD sample in addition to other COFP conditions)	Moderate confidence
9. TMD affected completing daily activities: having TMD affected a range of daily activities such as: chewing, talking, yawning, and singing. In addition to low sleep quality, energy, and concentration levels	Thirteen studies ³⁰⁻⁴²	Minor concerns (2 of 13 studies have low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (five studies included a TMD sample in addition of other COFP conditions. One of which consisted of elderly people. Two studies consisted of adolescent patients.)	High confidence
10. TMD caused psychological distress: negative feelings emerged throughout the journey of dealing with TMD. Starting with anxiety before diagnosis, frustration with the clinical interactions, irritation at the lack of effective pain control and later depression and melancholy at the difficulty of coping with the pain	Fourteen studies ^{26-29,32-39,42,43}	Minor concerns (1 of 14 studies have low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (three studies included a TMD sample in addition to other COFP conditions. One study consisted of adolescent patients)	High confidence
11. Plausible explanations for TMD: Patients expressed their understanding of TMD as a part of a larger complex problem that might be difficult to comprehend. Once they found an explanation, they tried to reinterpret past events to fit into that explanation. Some of the perceived causes were trauma and dental work.	Eleven studies ^{27,29-31,35-38,43-45}	Minor concerns (2 of 11 studies have low CASP)	Minor concerns (This pattern is not explored in detail; hence other patterns may emerge if explored further)	Minor concerns (The finding is complex and could be explored in more detail)	Moderate concerns (three studies included a TMD sample in addition to other COFP conditions. One study consisted of Sami women. One study consisted of adolescent patients)	Moderate confidence
12. Views on TMD: TMD was viewed in a positive or a negative outlook. Positive if they were able to use it to make changes in life, and negative if concerns over the fluctuating nature of the condition persisted even after some pain control	Four studies ^{33,36,37,40}	Serious concerns (two of four studies have low CASP)	No or very minor concerns	Minor concerns (The finding is complex and could be explored in more detail)	No or very minor concerns (one study consisted of a TMD sample in addition to other COFP conditions)	Low confidence

TABLE 3 (Continued)

Summary of review finding	Studies contributing to review finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual overall assessment
13. Stigma: some patients linked TMD with stigma and preferred not to mention it to other people. Other patients did not perceive stigma in association with TMD	Three studies ^{34,37,40}	Serious concerns (two of three studies have low CASP)	No or very minor concerns	Minor concerns (Not richly described in the studies)	No or very minor concerns (one study consisted of a TMD sample in addition to other COFP conditions)	Low confidence
14. Pain is a dominant entity: pain was overwhelming on occasions, both physically and psychologically. Some patients found it difficult to plan and progress in life	Eleven studies ^{27,28,30,31,33-37,39,40}	Minor concerns (2 of 11 studies have low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (four studies included a sample of TMD in addition to other COFP conditions. One Sample consisted of Sami women. Two studies consisted of adolescent patients)	High confidence
15. Adapting and moving on: patients were able to cope better with the pain if they received a diagnosis, a reassuring consultation, support from surrounding people and engaged in physical activity	Twelve studies ^{27,28,30-35,37,39,40,42}	Minor concerns (2 of 12 studies have low CASP)	No or very minor concerns	No or very minor concerns	Moderate concerns (five studies included a sample of TMD in addition to other COFP conditions. One study consisted of Sami women. One study consisted of elderly people. Two consisted of adolescent patients).	High confidence
16. Aims and hopes: some patients did not expect complete reversal of symptoms, whereas others wished for total alleviation	Six studies ^{26,27,30,36,37,39}	Minor concerns (one of six studies have low CASP)	No or very minor concerns	No or very minor concerns	Minor concerns (one study consisted of Sami women. Two studies consisted of adolescent patients)	High confidence

Difficulties were also reported on the partners' behalf, as they could often be unsure of how to deal with their pained spouses.^{34,40} Supportive attitude was definitely shown by some partners. They recommended seeking professional help and suggested treatment strategies.^{29,32,40}

4.2.3 | Professional life

Declined job performance was a concern on occasions. It felt too taxing and energy consuming to maintain a career. So, pursuing career advancements was abandoned, and seeking less demanding jobs, rejecting career goals or eventually quitting seemed like the only options.^{26,29,34-37,40} They also reported having to take more frequent sick leaves.^{31,34}

"I just turned down a job that I would not have the physical stamina to do. It's changed my world view, in that I think, in that I have to think of my health as a primary consideration where it wasn't before." (Ellen, 38- TMD).³⁷

4.2.4 | Financial burden

Financial implications were also revealed. The cost of repeated consultations and alternative treatments caused loss of earnings and in extreme cases, bankruptcy. This, in association with effects on career prospects, could cause extreme hardship to some patients and their families.^{34,36,38}

"I have had to pay for everything; virtually I am bankrupt trying to get to the bottom of it." (Patient 4).³⁸

4.2.5 | Daily life

Some patients stated that having TMD did not stop them from doing things most of the time.^{34,40} For others, however, it affected the ability to chew and enjoyment of food. They had to be careful selecting their meals as food is a common trigger for pain, and it could be embarrassing to eat in public due to the clicking noises or the need for a long time to eat.^{30-32,34,38,39,41,42} It also intruded on other important aspects of life, such as sleep quality, carrying out routine activities, ability to talk, yawn, kiss and sing.^{31-33,35-38,40,42} They also reported low energy levels, loss of productivity, difficulty concentrating, digestive complications, weight changes and diet modifications.^{31,33-36,39-41}

"It affects everything... affects me being able to talk... eating is exhausting, it takes so long to eat and the pain, it like pulls me down and makes me tired." (Patient 3).³⁸

4.3 | TMD causes distress

This theme describes the array of feelings which arose when trying to cope with chronic pain. They ebbed and flowed throughout the clinical journey and interactions with surrounding people.

Patients reported feelings of anxiety, possibly starting as early as the beginning of symptoms due to the bewildering nature of pain.²⁹ They drew on personal experiences in an attempt to rationalise the pain, and often, grim explanations came to mind feeding into the circle of worry and uncertainty.^{26,32,34,43} Patients also reported feelings of discomfort in their own bodies and 'jealousy of normal people'.⁴²

A part of these sentiments was also directed towards the clinical process they encountered.^{27,28,34,35,42,43} Some experienced lack of diagnosis, lack of empathy from the doctors and the absence of guidance about treatment. The sense of abandonment and being passed around also gave rise to feelings of hopelessness and helplessness.^{28,34,38}

Psychological turmoil continued later as well, with patients expressing feelings of irritation and depression due to ineffective pain control, frustration and anger at the unfairness of life and despair at the prospect of spending the rest of their lives in pain.^{26,29,32,33,35-39} Some completely lost hope which drove them to feel melancholic and hint at suicidal thoughts.^{32,33}

"Sometimes I really want to die...Why do I live so long? I believe that the (jaw) pain could only be solved if I die. I always feel annoyed and depressed...Why is life so tough? I think it's unfair for me to live so long and suffer from the pain!" (Female participant, age 71, with both severe jaw and tongue pain for 3 years).³²

"I mean this is nothing but a miserable, humiliating, and embarrassing living hell." (Paul, 36-TMD).³⁷

4.4 | Understanding TMD—the illness and the causes

4.4.1 | Plausible explanations

Patients expressed their understanding of TMD as a part of a larger complex problem that might be difficult to comprehend.^{37,44} They wanted to make sense of it, so they tried to find a physical cause to reconcile with their symptoms.^{30,36-38} Once they found an explanation, they tried to reinterpret past events to fit into that explanation.³⁷ Some of the perceived causes for TMD included: local injury to the facial area, hereditary connection, dental work, parafunctional habits and jaw strain.^{27,29,30,35,36,38,43}

"So you wonder, is it something hereditary, is it something in our genes that caused it, or just what is it?"³⁷

"I think it might be through having loads of dental treatment from a young age.... I have had dental treatment since I was about six." (Patient 2).³⁸

Patients had conflicting views on the role of stress and psychological health as a possible contributing factor. Some accepted this model early in their history and pointed it out in their interviews,^{27,31,35-38,43} while others refused it completely.^{36,37,45}

"I believe that it is something I do when I am stressed, so then I address the tension, what caused it, and I do something about it. It manifests itself here [while pointing at jaw]. For someone else this may be the neck. I would first try to figure it out for myself." [interview 13- TMD].³¹

"Have you been under any pressure lately?" As one person explained, "... they kind of just turn it on you in a way, by saying it's all stress-related and it's like you're causing it yourself." (TMD patient).³⁶

4.4.2 | Views on TMD

TMD was perceived negatively by some patients. Even if treatment was effective, concerns over possible future exacerbations cropped up. They described it like 'having a sword hanging over your head' because they did not know when the next episode is going to happen. They also imagined it as a punishment that may occur even if one is assertive of progress.^{33,36,37,40} Additionally, facial pain was described as a class of its own, where it is considered more psychologically distressing than other types of chronic pain.³³

*"I don't know why, but it feels as if I have been punished. It is exactly as if He is sitting up there and laughing".*²⁹

"You often wonder, when you're pain free, how long are you going to go on this way before it flares up again. You say to yourself, well, this is great, I wish I could be this way. But it's like, you know, when is the next time?" (Carol, 38- TMD).³⁷

Other patients tried to have a more positive outlook, where they chose to take the pain and interpret it in way that encouraged them to make changes in life. Some even saw it as a 'learning experience that made life more rewarding'.³⁷

"I can't help but feel like not that there's a purpose to my pain, but that I haven't let it triumph. I've made it into something else. I've made it into a way to make connections to people." (Gail, 37- TMD).³⁷

4.4.3 | Stigma

Stigma was associated with TMD in some cases, where they preferred not to mention it to others for fear of being seen in a certain way. They did not want to assume the identity of a chronic pain patient.^{34,37,40} However, that was not always the attitude, and some might perceive no stigma in association with TMD.⁴⁰

"I didn't want them to say we've got a lunatic on our hands here, cause we know what that's about. Some people think it's all in your head, it's mental." (Carol, 38- TMD).³⁷

4.5 | Now what? Dealing with TMD

This theme describes the approach to dealing with TMD. Personal attitudes towards this condition fell between two poles on a spectrum, and this position could shift depending on circumstances, such as the nature and severity of the pain.³⁵

4.5.1 | It is a dominant entity

Pain was sometimes described as an all embracing and a dominant entity in life, both physically and psychologically.^{33,34} They had a need to control their symptoms to be able to move on and live again, and it felt like a full-time job to do so.^{36,37,40}

Search for an answer is an "ongoing thing that never ends, it's never going to end until I get better" (TMD patient).³⁷

Patients described the overwhelming nature of the pain, where sometimes it was difficult to get up in the morning and find the energy to go through the day.^{33,35,39,40} Routine tasks became daunting to do, and some had to rearrange their lives to avoid triggers.^{31,34,40,42} Pain had an unpredictable nature; therefore, it was hard to plan life. They felt stuck with the pain which consequently caused passivity in life.^{27,28,33} Meanwhile, they reminisced about their old lifestyle and were preoccupied with the pain, even if it was absent.^{34,37,39}

"Most of my energy is kind of being used up trying to either ignore or fight the pain or something, so there wasn't much left over to socialize even or anything" (Theresa, 23-TMD).³⁷

Feelings of fear, hopelessness, anxiety, anger, irritation and loss of self-identity were frequent.^{31,34,36,37,39,40,42} Fear of the symptoms being out of control, hopelessness of any improvement in the future, disappointment due to lack of effective pain control and anxiety that something treatable had been missed.

"That I will go back to where I was, when the pain was out of control and it will never get

better and it will just, I will just live in that pain and be just completely like a total prisoner of pain.” (Kay, 37-TMD).³⁷

“Your mind is always, even when you try to get your mind off it, it's very quickly brought back to it. You fight with it and you lose, you lose the battle every time, every time” (Debbie, 39, TMD).³⁷

4.5.2 | Adapting and moving on

Some patient groups were able to be more accepting of the symptoms. Pain was acknowledged as an ‘immovable fixture of life’ but they learned how to bear it and move on.^{27,31,32,34,37,39,45}

Some of the useful elements which helped in coping with the symptoms was receiving a diagnosis, getting information about TMD and a reassuring consultation. They were able to ignore the symptoms by staying connected to surrounding people, engaging in any physical activity to take their mind off it, aiming to live as a healthy person and recognising their own role in healing. Partners, family and friends also helped in handling the symptoms.^{28,30–33,35,37,39,40,42}

“I could get out there socially and I could count on that, I could be some place and count on being able to. I decide when I'm going to leave, not my body.” (Debbie, 39-TMD).³⁷

“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, post-consultation- TMD and chronic idiopathic facial pain).²⁸

Some preferred silence in dealing with their symptoms, where they hid the pain and dealt with the physical consequences later.^{28,34,40} The reason for this behaviour was that they did not want to assume the identity of a chronic pain patient and did not want to burden anyone with it.^{34,40} They tried to ‘soldier’ through life and maintain a positive outlook.⁴⁰ Taking it 1 day at a time helped, as thoughts of the future could be terrifying.^{33,37,40}

“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.” (Hank, 65-TMD).⁴⁰

4.6 | Aims and hopes

This theme describes the aims of the patients, where there was a sense that it was important to gain some control over the pain.^{26,27} Some patients did not have high hopes

and realised that the symptoms will not be reversed completely.^{34,36,39} Others, however, wished for complete alleviation of the pain, and restoration of their lifestyle prior to it.^{26,30,36,37,39} They reported getting a ‘reality check’ after diagnosis as to the course of the illness, and feelings of disappointment and disillusionment at the treatment options and effectiveness.^{26,36,44} Life goals were suspended, and health improvement became the primary concern.^{36,37}

“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-TMD).²⁶

“I never expect to feel 100% well. If I just get rid of some of it, life will be better.” (P-4- TMD).³⁹

5 | DISCUSSION

Our findings suggest that TMD casts largely negative effects over the lives of the patients. Struggles may exist within oneself, but also permeate other facets of life, such as professional aspects and familial relationships. This resonates with quantitative studies which highlight the negative impact of TMD on several aspects such as: quality of life^{46,47} sleep quality with pain-related TMD,⁴⁸ depression, somatisation⁴⁹ and social impairment.⁵⁰ Qualitative reviews on the other hand offer a different angle to look at the evidence. They offer in-depth understanding of the condition as recounted by the patients themselves and rich interpretations relating to the impact of TMD on life. They also offer a valuable insight into the attitudes of patients, their social interactions and experiences with the health-care system. Moreover, they give the opportunity to present contradicting views about the same point, gathered from different studies.⁵¹

Our findings suggest that TMD pain can be psychologically challenging. Qualitative reviews of other chronic pain conditions present similar data.^{52–56} Feelings of depression, anger, helplessness, anxiety and guilt are described, as these patients try to negotiate their way in a new reality.^{52,57,58} Toye et al. describe the struggle of a ‘new’ self, imposed involuntarily as a result of the pain. The patient labours to prevent the erosion of the real self, and looks nostalgically to a past without pain.⁵⁸ The unpredictability of the future causes fear as well; fear of potential worsening of the symptoms, of reliance on medications, of letting surrounding people down and of stigma.⁵⁸

Another theme that is shared in chronic pain is the struggle to be believed. In many cases of chronic pain, there is no tangible evidence of pathology, and consequently, patients battle to validate their pain experience. This may give rise to feelings of doubt that permeates their experiences with family members, work colleagues and healthcare providers.⁵⁸ A positive healthcare experience is therefore important to move forward with the pain.^{52,57}

This experience forms a large part of the life of a chronic pain patient, and it needs to be a pleasant one away from feelings of guilt and blame.⁵² Receiving a concrete diagnosis helps in this aspect, as it promotes feelings of legitimacy and enables them to seek support from family and friends.⁵⁸ Lachapelle et al. report in their study of patients with fibromyalgia, that a delay in diagnosis could lead to the destruction of the social network of the women enduring it.⁵⁹ Feelings of loss of credibility and being socially stigmatised were also reported.⁶⁰

Such as with other chronic pain conditions, our findings suggest that TMD imposes financial challenges. It is suggested that chronic pain creates economic impacts not only directly for the patients but also for governments due to greater need of sick leaves, reduced levels of productivity and the greater risk of leaving the labour market.⁶¹ A US study reported lost productivity amounting to \$61.2 billion per year caused by common pain conditions such as musculoskeletal conditions, back pain and headaches.⁶² Other reports also reviewed the financial impact TMD has on patients in the northeast of England and found that the total costs per 6 months range from £321 to £519 per individual.⁶³ Several direct and indirect costs were implicated, such as specialist consultation costs, employer-related costs due to work loss and presenteeism, that is, 'reduced productivity due to problems with concentration or decision making while at work'. In addition to the challenges imposed on the individual, the group also suggests added pressure on the economy, not only through lost productivity, but also due to the disorganised pathways of the healthcare system in dealing with chronic pain patients.

The methodological rigour of the included studies was generally acceptable, and the authors did not feel the need to exclude any of the articles based on quality. Methodological limitations did, however, exist. Perhaps most notably is the segment related to the influence of the interviewer on the participant (Item 6 in the CASP checklist). This falls under what is known as 'reflexivity' in qualitative research, which means "turning of the researcher lens back onto oneself to recognise and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation".⁶⁴

The major findings reported in this review were supported by multiple studies. Furthermore, the CERQual-GRADE assessment showed that the majority of findings had moderate to high confidence, meaning that it is likely/highly likely that the findings are a reasonable representation of the phenomenon of interest.²¹

6 | LIMITATIONS

The authors relied mainly on six data bases and included articles in English only. This may have introduced some publication bias, as other relevant studies may have been missed.

Sensitivity analysis was not formally conducted to assess whether the exclusion of the studies with lower CASP scores had any effect on the results.

An argument against qualitative synthesis is that it may take the reader too far away from the primary experience, as it contains interpretations (third-order constructs) of interpretations (second-order constructs) of the first-order constructs as relayed by the patients.⁶⁵ However, this move away beyond the primary studies is identified by some as the key feature of qualitative synthesis.^{19,20} In the words of Margarete Sandelowski, "*metasyntheses are integrations that are more than the sum of parts, in that they offer novel interpretations of findings. These interpretations will not be found in any one research report but, rather, are inferences derived from taking all of the reports in a sample as a whole*".¹⁹ We also ensured to preserve the context by presenting details of each primary study to enable the reader of judging the transferability of the findings to their own setting.

7 | CONCLUSIONS

This review aims to increase our understanding of the experience of living with TMD. It highlights the profound effects it could have on work, family, financial and social lives, and confirms the psychological and mental challenges encountered. It is therefore important for healthcare professionals to recognise these effects when dealing with such patients. They may already suffer alterations to their quality of life by the time they present to a clinical setting, and since the clinical journey is a major part of the life of a chronic pain patient, it is important that it is a positive experience.

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CONFLICT OF INTEREST

The authors declare no conflict of interest in relation to this piece of research.

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