Healthcare priorities in patients with chronic facial pain of temporomandibular disorders.

Running title: Healthcare priorities in patients with TMD.

Key words: Temporomandibular Disorders, Chronic Pain, Qualitative Research, Focus Groups, Delivery of Health Care, Experiences.

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Date of submission: 30/10/2022

Abstract

Objectives: to explore the experiences of patients with TMD with the National Health Service and to discover their healthcare priorities when seeking treatment. **Methods**: Semi-structured interviews were used. They were directed using a topic guide covering subjects such as initial visits in primary care, referrals to secondary care, and effect on symptoms. The discussions were audiotaped and transcribed verbatim. Thematic analysis was utilised to analyse the data. **Results**: 15 participants took part in three focus groups. Six themes were identified: “access to appropriate care”, “organised and coordinated care”, “receiving a diagnosis and enough information”, “interaction with the clinical staff”, “treatment strategies and having an ‘action plan’”, and “support and social networks”. **Conclusions**: The participants gave accounts of the difficulties encountered in healthcare in general terms and specific to TMD. Most notable

was the struggle to access appropriate care, receive a diagnosis and be understood. Our findings suggest that delays in delivering appointments with people of expertise may have caused worsening of symptoms. However, when a pleasant experience was encountered, access to care was fast, the clinician was understanding and communication with the clinical team was good. These provided positive experiences and were appreciated by the patients.

Background

Temporomandibular disorders (TMD) are a group of conditions that affect the temporomandibular joint, the surrounding musculature or both. They are the third most common cause for chronic pain after headache and backache and may affect up to 30% of the population, with a peak incidence between the second and third decades in life (J Durham et al., 2013). They usually manifest as pain in the temporomandibular joint or surrounding muscles, jaw locking, joint sounds, limitation in the range of movement, headache and earache (J. Durham, 2013; Murphy, MacBarb, Wong, & Athanasiou, 2013). In some cases, the onset is acute and self-limiting. In other cases, however, the symptoms are persistent, developing a chronic pain condition with similar behavioural, psychological, and psychosocial challenges to chronic pain conditions elsewhere in the body (Parker, Holmes, & Terezhalmy, 1993; Scrivani, Keith, & Kaban, 2008).

Previous literature suggests that patients with chronic pain engage frequently with healthcare services for several reasons, such as unsatisfactory clinical encounters and persistent search for effective pain control (Campbell & Guy, 2007; White, Williams, & Leben, 2001). The clinical journey is considered a major part of the lives of these patients with chronic pain; hence it is important that it constitutes a positive experience (Fran Toye, Seers, & Barker, 2019). In fact, the patients' feedback on the experience they encounter in healthcare services is established internationally as a marker of quality and a good source of information for improvement schemes (Raleigh et al., 2015). It seems however, that patients with chronic pain frequently experience unsatisfactory clinical encounters (Dima et al., 2013; F. Toye et al., 2013; Fran Toye et al., 2019; Fran Toye, Seers, Hannink, & Barker, 2017). Similarly, previous reports have highlighted notable inconsistencies and inefficiencies in the UK care pathways for patients with chronic orofacial pain resulting in delays in diagnosis and effective treatment (Breckons, Bissett, Exley, Araujo-Soares, & Durham, 2017).

Qualitative research aims to provide an in-depth understanding of real-world problems and people's experiences. It studies phenomena in the context of individuals and groups (Moser & Korstjens, 2017) and offers a more flexible approach in exploration of a phenomenon than quantitative research (Korstjens & Moser, 2017). In pain studies, it can be an effective means of investigating certain aspects that may be inaccessible using other approaches (Osborn & Rodham, 2010). Hence, a qualitative approach was chosen for this study in the form of focus groups. The aim was to discover the healthcare priorities of patients with TMD while seeking treatment for their symptoms within the National Health Service (NHS) in England and to explore their experiences with the healthcare system.

Materials and methods

This study was a part of a project to develop a patient reported experience measure (PREM) for TMD patients which received ethical approval from the Southeast Scotland Research Ethics Committee 1 (REC reference: 19/SS/0130) and the Health Research Authority (HRA) prior to data collection. It was conducted in accordance with the Declaration of Helsinki.

The qualitative component described in this article was reported according to the Standards for Reporting Qualitative Research (SRQR) checklist.

Participants

The participants in this series were patients with pain related TMD, diagnosed by facial pain specialists in a tertiary medical centre in central London with a facial pain unit. The diagnosis was later confirmed by the research team and the participants were classified according to the Diagnostic Criteria for TMD (DC/TMD). Purposive sampling was used to select patients who had persistent jaw problems (> 3 months), were over the age of 18 and had a good command of the English language. Eligible participants were approached after the conclusion of their routine clinical appointments at the facial pain unit and were informed about the study verbally and provided with a patient information sheet. If they were willing to participate, they were booked into a focus group at a convenient timing. The consent form was completed remotely in line with the guidance of the HRA.

There are no uniform recommendations regarding the ideal number of participants in focus groups. Some researchers proposed focus groups with 4 to 12 patients (Doria et al., 2018) , while others 4-6 participants (Tausch & Menold, 2016). Therefore, five patients were recruited for each focus group in this study. The number of focus groups depended on the point where data saturation was reached and no new themes emerged. (Gill, Stewart, Treasure, & Chadwick, 2008)

Data collection

The group discussions took part using an online platform in response to the SARS-CoV-2 restrictions at the time of conducting the study. Data collection took place between May - September 2020 and continued until data saturation was reached. According to Glaser and Strauss "*Saturation means that no additional data are being found whereby the sociologist can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated" (Glaser & Strauss, 1967).* Data saturation was reached after holding three focus groups as no new themes emerged in the third interview. The interviews lasted between 66-81 minutes (mean 71.6 minutes), and were audio recorded.

The discussions were conducted by two moderators (RNR and DT), who were both present during all focus groups. Both interviewers introduced themselves as researchers and were not involved in the clinical care of any of the participants out of concern that they would hesitate to discuss any negative experiences. At the interview, they took care to avoid allowing their notions and expectations to influence the participants' answers. Both interviewers are clinicians and are trained in qualitative research.

Semi-structured interviews were used to elicit data from the participants as it is a flexible way to obtain open ended data but within the scope of guiding and predetermined questions (DeJonckheere & Vaughn, 2019). The interviews were directed using a topic guide that covered a range of subjects, such as initial visits in primary care, referrals to secondary and tertiary care centres, experience using NHS services in England and effect on symptoms along the way. Follow up and probing questions were also used to prompt further exploration of a specific idea or thought. The guide was adjusted as the interviews progressed to elicit the data most suited to the aims of the research. The data from each focus group was analysed before the subsequent interview was conducted.

Data analysis

The interviews were transcribed verbatim. First, the researchers familiarised themselves with the data by listening to the audiotapes and making reflective notes and initial impressions. Thematic analysis was then utilised to identify the common themes among the groups. Line-by-line coding was carried, whereby the data was labelled into units to help identify patterns. The codes were then grouped together if they had similar content to form common categories. The process of theme identification is largely an active and interpretive process (Kiger & Varpio, 2020). Therefore, they were derived using an inductive iterative approach where the coded data was combined, analysed and interpreted. A narrative description was later given to each theme. To increase the trustworthiness of the findings, data triangulation and audit trails were used. The data was also later analysed using framework analysis for the purposes of the PREM development. The NHS patient experience framework was used as a basis for the analysis (NHS, 2011).

Results

Participants

A total of 22 participants were invited to take part in this study (19 females, 3 males). However, due to scheduling conflicts (n=5), and unwillingness to engage via an online platform (n=2), 15 participants consented to take part in the focus groups (14 females, 1 male) with an age range of 19-79 years (mean age 47.6 years). The details of the participants are listed in table 1.

Themes:

Six themes were identified after the analysis. Table 2 displays a summary of the themes and findings. The identified themes were as follows -

Theme 1: Access to appropriate care

Many patients encountered lengthy periods of time before receiving effective care. ***Frequent engagement in healthcare services*** was often reported before reaching the right clinical team where they sought several healthcare providers and engaged in multiple clinical visits. They reported oscillating between their GPs and dentists because each considered TMD to be the others' speciality. Frustration was often the result, as they were being passed around with no real help. Once they reached the right clinical team however, the healthcare experience became much more positive.

"Then I was going to the doctor, and he was sending me to the dentist, and the dentist sent me to the doctor, and it was just like a merry-go-round of nothing really happening". (010)

"So, I had the dentist and the GP, and the physio as well because I just couldn't bear it any longer. I was just in so much agony that I went and booked myself into a physio clinic to try and sort it out" (005)

Other reasons for the repeated clinical engagement were the lack of diagnosis and explanations, multiple onward referrals to different services and having to seek private care in the hope of receiving a diagnosis and definitive treatment.

"Then I still had it and I went to the doctor, and he really didn't know what to do really. He hadn't come across it before. Then after months of going back and forward and back and forward, I was referred to the dental hospital". (015)

The referral patterns which the patients experienced from primary care also seemed to be inconsistent. Some participants reported uncertainty on the part of primary healthcare professionals regarding the appropriate centres for managing chronic facial pain, leading in turn to multiple referrals to several centres. In other cases, the patients had to search online to identify medical centres which dealt with their symptoms and asked to be referred.

"I think my GP referred me to two or three different places at the same time, because she didn't know where to send me. I went to them all, and then without knowing they'd been all like, no, we don't take TMD patients." (006)

"I did my own research, and then asked him [dentist] to refer me, but I probably wouldn't have been here if it wasn't for me doing my own research". (010)

Some also faced administrative issues along the way where the referrals were caught in red tape. They did acknowledge, however, the nature of care within the NHS and therefore tried to set their expectations accordingly. In some cases, waiting for the initial appointment with a specialist was a long process, stretching up to 18 months. This extended period of waiting could result in worsening of symptoms and adding to their stress and frustration.

"After six months realising that the referral had been done wrong meant that everything had to be started all over again. For me, obviously the pain hasn't improved, it got worse." (003)

"I was referred I think by my dentist last year, and to date I haven't actually had any treatment" (004)

Another aspect of access highlighted was in ***cases of emergency***. Patients with TMD might experience sudden locking of the jaw or episodes of intense pain. They were aware of the long-term nature of care but would also appreciate prompt access in cases where they need extra support or help urgently.

"So, there was no emergency place, which I found really, that's what I needed, and it wasn't there". (006)

Theme 2: Organised and coordinated care

The participants discussed several aspects to well-coordinated care, such as organised appointments, and good coordination between the different clinicians looking after them. Often in the NHS, the patients might be followed up by a different clinician for the same problem. Dissatisfaction arose in cases when the new clinicians seemed uninterested, offered different input to their regular ones, or when the previous medical notes were not checked, using much of the consultation time discussing the history of the complaint again.

“I’d come in and I wouldn’t be seeing my regular doctor, and I had to keep explaining myself, and on one occasion I was actually discharged from the hospital because the doctor that I normally see wasn’t there”. (007)

“When I keep coming in, you know, I would be seeing different people, and that was really stressing me out, and the stress does make my situation a lot worse”. (007)

Prompt access to regular appointments, especially when having flare-ups of symptoms was also important. Unexpected cancellations of appointments without sufficient notice, and discharge form services without prior knowledge was understandably upsetting when they occurred. Reminders of the appointments beforehand were also found useful.

Theme 3: Receiving a diagnosis and enough information

Another strong theme that emerged was the importance of receiving a diagnosis. Very few participants received a sure diagnosis early after first experiencing the symptoms. In many cases, it wasn’t received till they reached a tertiary care centre which was two years after the onset of symptoms for some. Receiving a diagnosis meant that things could start moving and management can commence. It also led to relief and put their mind to rest after being confused by the symptoms for a long time.

“Well, I’ve had it now over 30 odd years. So at first, no, no one seemed to know much about it at all.” (013).

“So, it was really a relief for me to find out that at least now they can give me treatment for my problem” (002)

Receiving adequate information about TMD was equally important to patients. They appreciated dealing with knowledgeable and informative clinicians and welcomed the extra material given at the end of the clinical visits in the form of leaflets. These handouts helped understand their condition better especially as not all the oral information were grasped during the consultation.

“Well, I think the doctor that I saw gave me a handout which I find really good because when you’re at the appointment you don’t always take everything in. And so, when you get home you can read about it” (014).

Theme 4: The interaction with the clinical staff

Recognition of suffering was one of the subthemes that emerged strongly in the three groups, where there was a need to be believed, listened to, and taken seriously by healthcare professionals. They expressed a need to be understood and for their symptoms not to be downplayed or dismissed. For some participants, the effects of TMD were profound on their lives. However, several encountered negative experiences where they were turned away and were told the symptom were in ‘their mind’. They felt frustrated trying to explain the pain and encountered primary healthcare providers who became annoyed with them and suggested dealing with the symptoms on their own.

“I just got used to the pain, I guess, because it felt like no-one was really taking it seriously, and they didn’t understand the symptoms, and didn’t understand the impact it could have on your life” (010)

“And you know, just knowing that somebody actually is treating it seriously helps to cope” (001)

One participant recounted an extreme case where she was told she ‘was lying’ about her symptoms because her jaw was working normally. She became desperate and helpless that no one was ever going to help.

“He told me I was point blank lying because it couldn't be my jaw because I could talk, so it wasn't anything to do with my jaw, it was all in my head basically”. (011)

Unsurprisingly, the ***interaction with the clinician*** played a big role in the clinical experience. They felt reassured when the clinician offered enough time for each patient and ensured the information was understood. These qualities made them feel supported, made the hospital experience very positive and helped them cope better with the pain.

“And to know that you’re under the care of people that know what they’re doing, what’s going on with your condition. I think that’s quite reassuring”. (007)

“The first time I felt I wasn’t being listened to, and I think with this kind of condition it’s very important that the patient feels that they are being listened to”. (007)

On the other hand, clinical interactions could be a source of stress. Such as when trying to convince the clinical team of the sincerity and impact of the symptoms, when no reassurance and diagnosis were offered after several visits, or when treatment was delivered in a slow and rigid manner.

“I mean, there have been occasions when I felt that I haven’t been understood, and it’s been related to other issues, and that’s been quite upsetting” (007)

Good communication with the services was also welcome among the patients. Patients were left frustrated by lack of communication about referrals, appointment allocations or cancellations, and treatment plans.

Theme 5: Treatment strategies and having an ‘action plan’

Views on treatment strategies varied among the patients. While some preferred immediate pain relief, others preferred sustained long-term solutions with a holistic approach.

Another positive element was having an ‘action plan’. Knowing that the clinician was willing to try alternative options if one does not work was reassuring. They also appreciated the accompanying explanations with each management strategy and the participation in the decision- making process. Some were left disappointed when this was not the case, as they might have been expecting certain treatment options and were left wondering why those options were not offered.

“I think they relieved my stress a little bit, because now I can try all these different options, and if they don’t work then I can just come back, and we can try something else”. (010)

The treatment options offered in primary care also had a varying degree of success. Some patients, however, reported ineffective, and in some cases, inappropriate treatment approaches, such as teeth extractions, antibiotics and forceful ‘jaw realigning procedures’ under sedation.

“And then they tried to knock me out, put me under, and they tried to realign my jaw thinking it had been dislocated and it was the worst experience, I felt like my jaw was just going to snap because they were putting so much force”. (011).

Theme 6: Support and social networks

The benefit of supervised group meetings was highlighted. Such discussions reassured the patients of the validity of their complaints and addressed some fears about the expected course of the condition. Even after a satisfying clinical encounter with a clear diagnosis, the whole picture may still be incomplete. So, these groups offered the opportunity to obtain more information and try new things.

“But it was probably one of the most positive experiences I had right at the beginning when I didn't really understand what was going on”. (012)

Interestingly, the involvement of family and friends in healthcare was not crucial to this group of participants. They may be a form of support, but not necessarily involved in the clinical care as most attend appointments alone anyway. They did acknowledge, however, that it may be crucial for other patients who need support, so were careful not to dismiss this area as an important part of the clinical experience.

“I don’t feel that that’s anything that relates to me. Nine times out of ten I always come myself and I don’t really need anyone (007)

Discussion

Qualitative research provides valuable insight into the patients’ experiences and could be used to inform clinical decision making and patient care (Tong, Morton, & Webster, 2016). One of the difficulties which may be encountered in a clinician-patient relationship, is the discrepancy in the level of perceived pain, leading in turn to a difference in the approach to the illness and the management strategy. Qualitative research is therefore an excellent tool to explore the important aspects of the pain experience that are inaccessible to other approaches (Osborn & Rodham, 2010). Qualitative research is also contextual, meaning that the setting of the research matters. This piece of research consisted of group discussions which took place online with patients with TMD, recruited from facial pain clinics at an NHS tertiary care centre in London. Some of the findings reported here may well apply to other settings, for example a different country. However, this may not always be the case, such as with findings pertaining to referrals and access to care. These may differ from one country to another, or even from one centre to another in the same city. Additionally, the qualitative researcher may also influence the findings. In fact it is sometimes said that 'the researcher is the research instrument' (Dodgson, 2019). This concept refers to what is known as 'reflexivity' in qualitative research, or " awareness of the influence the researcher has on the people or topic being studied, while simultaneously recognising how the research experience is affecting the researcher" (Gilgun, 2008). The researchers involved in data collection were both clinicians. However, they were not involved in the clinical care of any of the patients, to avoid influencing their accounts in case they had negative experiences with their caregivers at the hospital. Data analysis was likewise conducted by an 'outsider', who did not meet the patients prior to the relevant research activities. Moreover, the analysis process was documented, where a track was kept of the decisions made, in case these choices were to be revisited. Having said that, reflexive analysis remains challenging, where in the words of Finlay "It is all too easy to fall into an infinite regress of excessive self-analysis at the expense of focusing on the research participants" (Finlay, 2002).

Focus groups are a popular method in health research to gain perspective and understanding, whether it is patients' or clinicians' (Côté-Arsenault & Morrison-Beedy, 2005; Tausch & Menold, 2016). They are a useful method in topic exploration, questionnaire development and phenomenon descriptors (Côté-Arsenault & Morrison-Beedy, 2005). When done well, a great deal of information could be obtained from a small group of patients, and with guidance, participants can go back and forth in the discussion and produce a rich blend of perspectives (Côté-Arsenault & Morrison-Beedy, 2005) . Additionally, they might generate more ideas and give a wider coverage of a specific problem than individual interviews (Tausch & Menold, 2016). One of the main disadvantages of focus groups, on the other hand, is the extensive effort and time required to organise them. They could also suffer from over or under dominance of certain individuals. These problems, however, can be solved by intervening verbally or by having experienced moderators (Wiering, de Boer, & Delnoij, 2017b). Another aspect to consider when planning focus groups is the number of participants. The number should be large enough to gain enough understanding of the different opinions and perspectives, while small enough to allow everyone sufficient time to participate fully. (Côté-Arsenault & Morrison-Beedy, 2005). Hence, five participants were selected for each group in this study.

This series of focus groups aimed to increase our understanding of the aspects of healthcare which are important to patients with TMD. The participants gave accounts of the difficulties encountered both in general terms, but also specific to patients with TMD. As with other chronic pain conditions, they struggled in several aspects, notably the struggle to be believed and taken seriously. In many cases of TMD, there may not be tangible evidence of pathology, and the clinician relies mainly on the story of the patient. This disbelief is not only encountered in a clinical setting but may also extend to affect social and familial relationships (J. Durham, Steele, Wassell, & Exley, 2010; Hazaveh & Hovey, 2018). Patients might struggle to articulate the pain they are going through to family members, and ultimately give up trying to explain. A confirmed label to the condition may therefore help patients with TMD to a great effect. A diagnosis, along with a satisfying clinical encounter, a reassuring clinician and receiving enough information about the condition were important factors in the ability to cope and move forward with the pain. It offered reassurance of the legitimacy of their complaints and meant that things can take off in terms of management.

Frequent clinical engagement seems to be a genuine issue for patients with chronic orofacial pain (COFP). Breckons et al studied the clinical pathways of patients with COFP in the UK, and suggested that the current pathways do not meet the patients' needs (Breckons et al., 2017). A major problem identified was the lengthy periods to obtain a diagnosis and adequate treatment from first presenting with the complaints. Patients also reported repeated clinical attendance in primary and secondary care in search of effective pain control. The participants in this series of focus groups reported that they were bounced back and forth between dentists and GPs as each considered facial pain a part of the others' expertise. Primary care clinicians also referred to several specialities at one time, due to uncertainty about which centres or specialities deal with these kinds of complaints. This may have added unnecessary burden to the NHS and delayed access to effective treatment.

The NHS in England is a very complex healthcare system, which follows a socialised medicine model. It is provided by the government, however, funded by the taxpayer. First point of contact with the system is usually in primary care with the GP, or the general dental practitioner (GDP). Referrals to specialist services will be accepted if a referral letter was issued by the clinician in primary care (NHS, 2019). Multiple patients in this study reported several challenges, for example delays in accessing specialised services and inconsistent referral patterns. However, some of those issues were also reported in other healthcare settings. For example, Wolf and colleagues, reported in their phenomenological study of the experiences of patients with nonspecific COFP in Sweden, that some of the participants felt distrusted and viewed with suspicion by healthcare professionals (Wolf, Birgerstam, Nilner, & Petersson, 2006). Constant referral between dentists, doctors and specialists was also reported by TMD patients in the USA in a study by Eaves et al (Eaves, Nichter, Ritenbaugh, Sutherland, & Dworkin, 2015). Similarly, in Canada, some participants with OFP expressed dissatisfaction with the healthcare services, for example, due to lack of support within primary care, delays in diagnosis and difficulties in gaining access to care (Hazaveh & Hovey, 2018). These mirror some of the difficulties encountered by the participants of this study. Hence, it seems that some these issues may span different healthcare systems and countries.

Another aspect which might be of relevance, is the strength and quality of undergraduate training in COFP, whether in dental or medical schools. Some reports highlight the hesitancy of primary care clinicians in diagnosing and managing this group of conditions (J. Durham, Exley, Wassell, & Steele, 2007; Peters et al., 2015) Furthermore, healthcare professionals from different backgrounds, have varied approaches to managing TMD. For example, those who follow the biopsychosocial model of care, may recommend conservative treatment and psychological support, whereas oral surgeons may lean towards surgical procedures. Hence, one of the challenges facing patients with TMD is the lack of a “medical or dental home for TMD care” and lack of standardised referral patterns and treatment strategies for the patients displaying symptoms of chronic facial pain (National Academies of Sciences & Medicine, 2020). Improving the quality of undergraduate education, and indeed subsequent postgraduate training, around this area may play a role in improving the effectiveness of primary care in diagnosing and managing COFP.

The reported benefits from group sessions should also be taken into consideration. Our results align with previous accounts regarding their importance. For example, Ainsley et al report in their study that participants in a specialist facial pain management program found socialising with other patients with COFP comforting and helpful (Ainsley et al., 2021). This brings to the discussion the possibility of creating a regular supervised platform for these patients. The financial and logistical implications may well prevent such a regular exercise in most care facilities. However, with the increasing evidence of the benefit of these platforms (Farr et al., 2021; Subramaniam, Stewart, & Smith, 1999), it may prove to be cost effective in the long term in managing the mental and psychological wellbeing of these patients.

This study was conducted as a first step in developing a patient reported experience measure for patients with TMD. PREMs are tools to capture the patients’ perspective, therefore, their involvement in the development process is necessary (Fitzpatrick, Davey, Buxton, & Jones, 1998; Meadows, 2011; Wiering, de Boer, & Delnoij, 2017a; Wiering et al., 2017b). Lack of patient input may compromise the validity, sensitivity, and response of a questionnaire (Fossey & Harvey, 2001; Meadows, 2011; Wiering et al., 2017b). Future work involves the second phase of developing the PREM for patients with pain related TMD. The findings from this qualitative study in addition to a previous qualitative evidence synthesis will ensure data triangulation by collecting data from different sources and will be used to generate the items of the questionnaire. Later stages will also test the validity and reliability of the questionnaire using a quantitative design.

Limitations

The limitations to this piece of research include the inherent limitations associated with online focus groups. The design was amended in response to the SARS-CoV-2 restrictions at the time of conducting the study. Such limitations include technical difficulties and the disruption to the flow of the discussion in the case of loss of connection. Additionally, probing may prove a more difficult task, as the moderator may not be able to pick up on non-verbal cues and body language (Fox, Morris, & Rumsey, 2007). The participants however were comfortable using the chosen online platform and faced no technical issues during the recorded sessions. Data security was maintained by having passwords to protect the meeting. Therefore, no one without an invitation from the host was able to gain access to the meeting room.

Additional limitations are related to the sample used. The research team attempted to recruit a representative sample of patients with TMD as much as possible, by including participants of both genders, with positive and negative experiences, and new and follow up patients with a wide age range and diverse ethnic backgrounds. However, we were not able to recruit more male participants due to scheduling conflicts and unwillingness to engage in online discussions. This may affect the transferability of the results. It is worth noting however, that females are more likely to develop persistent TMD (Palmer & Durham, 2021; Slade et al., 2013), with a female: male ratio reported between 4-8:1 in a clinical setting (Bush, Harkins, Harrington, & Price, 1993; Drangsholt et al., 1999; Maixner et al., 2011). This may have skewed the sample in favour of female patients attending clinical appointments for treatment of TMD.

Some participants may have held back on their negative accounts out of concern that their feedback could reach their caregivers. However, they were thoroughly assured prior to taking part that the answers will remain anonymous and none of their clinical team members were directly involved in moderating the groups so as not to affect their willingness to share their views.

Conclusions

The participants gave accounts of the difficulties encountered in healthcare in both general terms and specific to patients with TMD. Most notable was the struggle to access appropriate care, to receive a diagnosis and to be understood. Our findings suggest that delays in delivering appointments with people of expertise may have caused worsening of symptoms. However, when a pleasant experience was encountered, access to care was fast, and communication with the clinical team was good. These provided positive experiences and were appreciated by the patients.

It may be worthwhile for future research to explore the effect of the different facets of healthcare on the perceived outcomes and measure the most influential aspects so as to prioritise them when and if attempts were made to correct the care pathways of COFP patients. Research could also investigate the possibility of promoting the NHS health centres which deal with COFP among primary care clinicians. This may result in faster referrals and help avoid unnecessary ones to centres which do not offer treatment for chronic pain. Revisions to the undergraduate curriculums of dental and medical schools may also have a role in improving the effectiveness of primary care in dealing with this group of patients.

Author contributions

RL contributed to the conception and design of the study, was involved in patient recruitment, in revising the manuscript critically for intellectual content and final approval of the version to be published. SF was involved in the conception and design of the study, in revising the manuscript critically for intellectual content, and final approval of the version to be published. DT and RNR contributed to the conception and design of the study, were involved in patient recruitment, moderated the online sessions, were involved in data analysis and interpretation, in manuscript drafting and revision, and final approval of the version to be published.

Acknowledgements

The authors would like to acknowledge the financial support provided by the University of Jordan, in the form of a PhD student sponsorship awarded to DT.

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

Table 1. Participants' details.

Number	Sex	Age	DC/TMD† classification	Group number
1	F	70	Myalgia and DDwR‡	1
2	F	79	Myalgia and arthralgia	1
3	F	39	Myalgia and headache attributed to TMD.	1
4	M	55	Myalgia and DDwR.	1
5	F	57	Arthralgia and DDwR.	1
6	F	22	Myalgia.	2
7	F	50	Myalgia, DDwR with intermittent locking.	2
8	F	19	Myalgia.	2
9	F	28	Myalgia, DDwR with intermittent locking.	2
10	F	25	Myalgia.	2
11	F	27	Myalgia and arthralgia.	3
12	F	50	Myalgia and Headache attributed to TMD.	3
13	F	71	Myalgia	3
14	F	43	Myalgia	3
15	F	79	Myalgia	3

† Diagnostic Criteria for TMD, ‡ Disc displacement with reduction

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Table 1. Participants' details.

Number	Sex	Age	DC/TMD† classification	Group number
1	F	70	Myalgia and DDwR‡	1
2	F	79	Myalgia and arthralgia	1
3	F	39	Myalgia and headache attributed to TMD.	1
4	M	55	Myalgia and DDwR.	1
5	F	57	Arthralgia and DDwR.	1
6	F	22	Myalgia.	2
7	F	50	Myalgia, DDwR with intermittent locking.	2
8	F	19	Myalgia.	2
9	F	28	Myalgia, DDwR with intermittent locking.	2
10	F	25	Myalgia.	2
11	F	27	Myalgia and arthralgia.	3
12	F	50	Myalgia and Headache attributed to TMD.	3
13	F	71	Myalgia	3
14	F	43	Myalgia	3
15	F	79	Myalgia	3

† Diagnostic Criteria for TMD, ‡ Disc displacement with reduction

Table 2. Main findings and themes

Themes	Findings	Supporting quotes
Access to appropriate care	• Frequent engagement in healthcare services was often reported before reaching the right clinical team.	*"Then I was going to the doctor, and he was sending me to the dentist, and the dentist sent me to the doctor, and it was just like a merry-go-round of nothing really happening". (010)*
	• Patients sometimes experienced inconsistent referral patterns from primary care.	*"I think my GP referred me to two or three different places at the same time, because she didn't know where to send me. I went to them all, and then without knowing they'd been all like, no, we don't take TMD patients." (006)*
	• Access in cases of emergency was highlighted as an important aspect.	*"So, there was no emergency place, which I found really, that's what I needed, and it wasn't there". (006)*
Organised and coordinated care	• Several aspects to well-coordinated care were mentioned, such as: organised and regular appointments and good coordination between the different clinicians.	*"When I keep coming in, you know, I would be seeing different people, and that was really stressing me out, and the stress does make my situation a lot worse". (007)*
Receiving a diagnosis and enough information	• Some patients reported delays in receiving a diagnosis.	*"Well, I've had it now over 30 odd years. So at first, no, no one seemed to know much about it at all." (013).*
	• A diagnosis meant that the management could finally commence.	*"So, it was really a relief for me to find out that at least now they can give me treatment for my problem" (002)*
The interaction with the clinical staff	• Recognition of suffering: Some patients had a need to be believed, listened to and taken seriously by the healthcare professionals.	*"I just got used to the pain, I guess, because it felt like no-one was really taking it seriously, and they didn't understand the symptoms, and didn't understand the impact it could have on your life" (010)*

	• Interaction with the clinician played an important role in the clinical experience. • Good communication with the services was very welcome among the patients.	*“The first time I felt I wasn’t being listened to, and I think with this kind of condition it’s very important that the patient feels that they are being listened to”. (007)*
Treatment strategies and having an ‘action’ plan	• Knowing that the clinician was willing to try alternative options if one does not work was reassuring. • They appreciated being involved in the decision-making process.	*“I think they relieved my stress a little bit, because now I can try all these different options, and if they don’t work then I can just come back, and we can try something else”. (010)*
Support and social networks	• The benefits of supervised group discussions with other patients were highlighted. For example, in addressing some of the concerns and obtaining new information.	*“But it was probably one of the most positive experiences I had right at the beginning when I didn't really understand what was going on”. (012)*