

Temporomandibular disorder patients' journey through care

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Abstract – Temporomandibular disorders (TMDs) are a common group of chronic disorders (illnesses) that health care providers can find difficult to diagnose and explain. Similar difficulties in the diagnosis of other chronic conditions have been shown to have a negative impact on health. An understanding of TMD patients' experiences and journey through care could indicate time points and strategies to help patients. *Objective:* To develop a robust empirically derived map of TMD sufferers' journey through care. *Methods:* A qualitative study using semi-structured interviews was undertaken using a purposive sample of patients with TMDs. Analysis followed the principles of the constant comparative method where data collection and thematic analysis occurred concurrently and continued until data saturation ($n = 29$). *Results:* The experiences of patients could be grouped into three key stages: genesis of problem, seeking help in primary care and secondary care intervention. A wide variety of negative effects were described throughout these stages. An empirically derived map of the patients' reported journey through care emerged. *Conclusions:* The experiences of patients with TMDs mirror experiences of other types of chronic illness. Mapping the journey through care for TMDs highlights the potential for interaction between the stages of the journey and the individual's illness. It may be possible to target interventions at specific stages on the map to help minimize the psychosocial effects of TMDs.

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Temporomandibular disorders (TMDs) are a recognized chronic illness (1). The term temporomandibular disorders is 'a collective term embracing a number of clinical problems that involve the masticatory musculature, the temporomandibular joint and associated structures, or both'. TMDs are considered to be a subclassification of musculoskeletal disorders (American Academy of Orofacial Pain). In the United Kingdom, it is suggested that 20–75% of the population have signs or symptoms of TMDs, but only 2–4% present to clinics for consultation and/or management (2). Evidence suggests that when sufferers of TMDs present to clinic, clinicians can find their symptoms difficult to explain or diagnose (3, 4).

The diagnostic process for those with apparently unexplainable symptoms can often be protracted involving multiple visits to the same or different

clinicians and multiple referrals before a diagnosis is reached (5–7). A similar characteristic has also been demonstrated in TMDs (8, 9). In other clinical settings, multiple visits to a singular clinician have been shown to have particular consequences. For example, the clinician may look for somewhere to 'dispose' of the patient via referral (10). Alternatively, the clinician may simply start to fail to hear, or recognize, the needs of the patient. Both of these consequences may have negative psychosocial impacts on the patient (11). Visits to multiple different clinicians seeking a diagnosis may stigmatize the individual even before they have had a consultation in specialist care; they may become perceived by some health professionals as the so-called heartsink patient, that is, they may be categorized as a demanding, troublesome or non-conforming, patient (12, 13).

Our previous qualitative research suggested that primary care dental practitioners could find TMDs difficult to diagnose and that dental clinicians feel TMDs can be difficult to manage (3). If patients with TMDs experience these professional perceptions of their illness, this may alter the effects or course of their illness. Establishing which experiences alter the effects or course of the illness may help identify key interventions and time points to reduce the impact of TMDs on patients' everyday lives. The aim of this paper is, therefore, to use the accounts of people with TMDs to explain the development of a robust empirically derived map of their journey through care. The map may then be used to identify stages in the patient journey through care where (simple) interventions could be made to improve the experience and lessen the impact of care pathways.

Materials and methods

The project received ethical approval from the local research and ethics committee (Newcastle and North Tyneside Ref 2003/83).

Sampling

Patients undergoing treatment for TMDs were recruited from a single British dental hospital. A nonprobabilistic purposive sample was used to try to capture a range and depth of experiences. The sampling criteria are shown in Table 1 with the rationale for their choice. Those individuals meeting the sample criteria were identified by their attending clinical team and were given a standard invitation letter and study information sheet. Those indicating an interest in participating were then followed up by the authors and given an appoint-

ment for interview. The interviews took place in comfortable nonclinical areas, and prior to the interview, written informed consent was obtained from the participant.

The characteristics of the sample are shown in Table 2. The age range of the sample was 18–65. The gender ratio achieved was four women to one man; this is a lower ratio of women to men than in the clinical population (14).

Interviews

Two trained interviewers conducted semi-structured interviews using a flexible topic guide. The initial topic guide was based on the domains of Locker's model of oral health (15), the chronology of the patient's experiences of their journey through care, and the clinical experiences of patients with TMD treated by clinical members of the research team. The topic guide evolved as data analysis occurred concurrent to new interviews. This evolution meant that it was possible with subsequent participants to explore points or issues that arose in earlier interviews.

The topic guide employed a variety of open-ended, nonleading questions to help stimulate narrative from the participant. For example, after a standardized introduction to the study, the opening question was, 'Please can you tell me a little bit about yourself and your family?' This question aimed to put the participant at ease and encourage them to talk freely. This question was followed, if necessary, by enquiring about their, 'First experiences with their problem'. Participants were allowed to talk freely with minimal interruption by the interviewer unless clarification of a statement was necessary for the purpose of the recording or further detail was sought. All interviews were digitally recorded, transcribed verbatim, checked for accuracy, and anonymized.

Table 1. Purposive sampling criteria and rationale

	Aim	Rationale
Gender	To achieve at least the UK M:F ratio presenting for treatment (7:1) in the sample (13)	To allow both gender's opinions and experiences to be included in the data collected
Age	A wide age range of patients to be included in the sample	To allow a variety of age groups to contribute to data collection to ensure disconfirming evidence did not emerge
Complaint <i>Diagnosis by criteria derived from the research diagnostic criteria (37)</i>	To include the main two generic complaints of TMDs, clicking and pain, in the sample	To ensure a variety of experiences of the effects of TMDs were included in the data collected

TMD, temporomandibular disorder.

Table 2. Sample characteristics

Patient number	Gender	Age	Diagnosis as provided by the attending clinician ^a	Main complaint
1	Female	65	MFPA, DD	Pain and clicking
2	Female	35	MFPA	Pain
3	Female	59	MFPA	Pain
4	Female	37	DD, MFPA	Pain and clicking
5	Female	52	MFPA	Pain
6	Female	54	MFPA, DD	Pain and clicking
7	Female	34	DD	Clicking
8	Female	47	MFPA	Pain
9	Female	33	MFPA	Pain
10	Male	38	MFPA	Pain
11	Male	33	MFPA, DD	Pain and clicking
12	Female	18	MFPA, DD	Pain and clicking
13	Female	48	MFPA	Pain
14	Male	48	MFPA	Pain
15	Female	26	MFPA, DD	Pain and clicking
16	Female	36	MFPA	Pain
17	Female	60	MFPA	Pain
18	Female	47	MFPA	Pain
19	Female	38	MFPA	Pain
20	Female	23	MFPA, DD	Pain and clicking
21	Male	58	DD	Clicking
22	Female	57	MFPA	Pain
23	Female	52	MFPA	Pain
24	Female	41	DD	Clicking
25	Female	46	MFPA	Pain
26	Female	47	DD	Clicking
27	Female	24	DD	Clicking
28	Male	42	MFPA	Pain
29	Male	33	DD, MFPA	Pain and clicking

All patients had greater than 3 months of treatment.

^aDiagnosis made by criteria derived from the research diagnostic criteria (37) and simplified into two groups: (i) myofascial pain and arthritides group (MFPA); (ii) disc displacement group (DD).

Data analysis

The interview and analysis process followed the principles of the constant comparative method (16) whereby data collection and analysis occur concurrently with one interview informing the next. The analysis process involved familiarization with the data through careful reading of the transcripts; development of thematic codes in which to organize the data; and developing conceptual links between the different codes (17).

Two researchers (JD and CE) were involved in the analysis process. JD developed the initial thematic coding frame using line-by-line coding, which was discussed and refined with CE (18).

Initially, the data analysis process first involved developing preliminary thematic codes from the transcript. These preliminary codes allowed the identification of recurrent experiences of individuals during care to be organized and a reported chronology of experiences to be developed. As

more patients' experiences were explored and more data were collected, the labelling of codes became more definite, and some codes were merged into larger codes. With continued data collection and analysis, the codes were refined and links between the codes and the reported chronology of events resulted in the emergence of a generic map of patients' journey through care.

The development of the map was an iterative process. All patients' data were assigned to the various stages of the journey on the most current iteration of the generic map; a worked example of this process for one patient on the final version of the map is available in Appendix S1. This 'plotting' of each patient's data onto the most current iteration of the map served two purposes: (i) it enabled the validity of the current iteration of the generic map to be checked for that particular patient; (ii) it allowed comparisons between participants to be made, which helped the development process. There were seven iterations of the map until the

map that emerged was relevant to all patients. Each version of the map was checked against the whole data set, reassigning relevant data to new or pre-existing stages, thereby ensuring the generic map was robust and applicable to every individual's journey. The emergent map related to the patients' accounts and experiences of their 'journey' through care. In line with the overall iterative approach to analysis, the map developed gradually after each interview with new pathways through care emerging until saturation, that is, when no new themes or pathways emerged. This occurred after a cumulative total of 29 interviews.

Results

The results are presented here using representative illustrative quotes to help support the theory developed. The number in parenthesis following the quotation can be compared with Table 2.

Sample

Thirty-four patients were approached in total and four declined the invitation to participate. All those declining gave their reason as insufficient time. One patient was not required for interview as saturation occurred previous to their interview.

Stages of the journey

The experiences of care the patients described could be categorized into three key stages:

- genesis of the problem
- seeking help in primary care
- secondary care intervention.

These three stages formed the foundation of the map of the patients' journey (Figure S1). Participants' explanation of the direct or indirect effects of their experience of care related to these three stages. In the following presentation of the results, the reported experiences of the sample are illustrated alongside the stages of the journey. Experiences that appear to be attributable to particular stages of the journey are highlighted, and the map of the journey through care will be explained in a stepwise manner (Figures S1–S4 and Fig. 1).

Genesis of the problem

All participants clearly identified the start of their complaint. However, not all could explain why it had occurred or could attribute a cause to the complaint. In all cases, the problem manifested as pain and/or mechanical dysfunction such as lim-

ited opening, locking or clicking of the jaw. Those with mechanical dysfunction tended to be able to attribute their complaint to their temporomandibular joint.

Well it's basically a lot of pain and a lack of opening. I've got quite a big mouth and it was all of a sudden it was very painful and restricted in movement. (Pt 15)

Participants experiencing pain without mechanical dysfunction often found it difficult to locate their pain because it radiated around their face. They struggled to explain the pain in words but always managed to communicate its severe unremitting nature.

When the pain is to the degree which mine has been, I've never been a down or depressive person in any form, but since that is the type of pain where, and discomfort, where it's impossible not to get down about...The type of pain even where there's times that I wished I was dead because the pain was just so unbearable. (Pt 9)

Descriptions of the onset of the complaint characterized it as either insidious or sudden. Mechanical dysfunction was often a sudden dramatic loss in mouth opening. This physical manifestation could legitimize the participant's complaint. Owing to the physical observable manifestation of their complaint, some individuals spoke about other people advising them to seek help.

Interviewer: When you came off the bus with your son and you had this lock, as you describe it, why did you go and see the dentist?

Patient: My husband...he [her husband] says you need to go to see your dentist...if I didn't have him [her husband], I would probably have left it [her "locked" jaw] for a while and then gone to the doctor. (Pt 24)

By contrast, those who reported pain often described an insidious onset. One common representation was of being initially aware that something was different or 'not quite right' but being unable to explain how or why. For some people, this insidious onset meant that they felt unable to discuss it with a health care professional, although some did discuss it with their friends or family. In this clinical sample, the pain had increased to disrupt their daily lives and they sought professional help.

Patients described their reactions to their complaint before seeking care. These reactions could be categorized into two overlapping groups. One reaction was to rationalize the cause of their problem in some manner. The other type of reaction was to experience psychological distress over the possible causes of their complaint.

Participants with locking, clicking, or ear pain had rationalized their conditions by constructing their own aetiological accounts based on their personal circumstance, experience and symptoms. These accounts did not necessarily accord with medical explanations.

Initially I thought maybe it was a dislocated jaw. I mean I'd dislocated my shoulder before and I just...and it kind of felt a bit similar. So I just thought oh it's [her jaw] come out, it's gone back in, maybe that's what it is (Pt 15)

Psychological distress occurred even before seeking care and might be related to (i) anxiety over the bewildering nature of the pain and (ii) pain intensity.

I thought well why am I getting pain and why is it going up the side of my face. I mean I've heard of neuralgia and all those kind of things, you know. But it was in the wrong place for that...Again it was my ears, I thought well my ears are alright. I even...—from time to time I've had...people look at my ears to see if they're actually alright just in case it was my ear (Pt 25)

Deep down, I think, in the back of my mind I was thinking what is really going on, is it something more serious than I really thought. You know, because of it lasting for so long (Pt 17)

The emergence of two subthemes (psychological distress and rationalization) gave rise to two possible routes for the journey through care before individuals sought help in primary care (Figure S2).

The structure of the UK National Health Service puts the general practitioner at the centre of health care. Initially, therefore, patients sought help from their primary care general dental or medical practitioner.

Seeks help in primary care

The recurring experience of primary care, irrespective of whether a medical practitioner or a dentist was consulted, was that respondents felt they had

left the consultation feeling ill-informed over the cause of their complaint.

They just kept looking at me teeth, they didn't say anything [about a diagnosis], just kept drilling into me teeth, injections and drilling me teeth all the time. (Pt 2)

For some, the primary care experience and lack of diagnosis heightened their concern over the cause of their complaint. Others reported relief that they were being referred to, 'get it sorted out' (Pt 14). Those reporting concern attributed this to either the ambiguity of the consultation with respect to a diagnosis or (irreversible) treatments that had been instituted and failed. The lack of information and ambiguity could result in interviewees feeling that their complaint lacked legitimacy, especially if they had seen more than one general practitioner.

Well I was going to the dentist every six months for a check up [whilst still in pain]. But I must admit I didn't mention it him. I felt as though I was being silly really because he said that my teeth were alright. (Pt 8)

I said "there's something you're not telling me about this [pain]" and he [the primary care practitioner] said "if I had any, you know, if there was anything [to tell you] you'd be away straight away", you know, he says "don't be stupid". But I mean I was getting where I was really, really down about this. I had said I be coming to your [the practice's] Christmas party because I'd been coming so often [about the pain]. (Pt 3)

The outcome of the primary care consultation could be as follows: (i) referral to the hospital (secondary care); (ii) referral to either their general medical practitioner (GMP) from the dentist or general dental practitioner (GDP) from the GMP, thereby establishing a potentially cyclic path; (iii) review by the attending GMP or GDP after (inappropriate) treatment. The lack of a diagnosis could exacerbate psychological distress because of fear over their complaint. Fears included the following: that surgery was needed; that you only go to hospital for 'major problems' (Pt 25); that there was a sinister cause to their complaint.

I saw [specialist after referral from primary care without diagnosis] and...he examined my mouth, obviously, and I had x-rays and so forth and he said what the problem [was]...there was obviously no real sort of

like cancer or anything like that which I was thinking (Pt 8)

The increased psychological distress and the possibilities of cyclic referrals in primary care led to two pathways in the map of their journey (Figure S3), both of which eventually led to secondary care intervention.

Secondary care intervention and TMDs' negative impacts on everyday living

Interviewees often recalled the wait after referral to be seen in secondary (specialist) care and explained that during this wait, they continued to experience symptoms and concern over their complaint. The continued symptoms and anxiety compounded the negative impacts of the illness on their everyday lives. Their prevailing desire during this wait, and upon attendance at secondary care, was to receive a diagnosis and explanation for their complaint, 'I didn't have this before now I have it. Why do I have it? I was then told what it was [in secondary care].' (Pt 21).

After the genesis of their problem, and throughout their wait for diagnosis, participant's problems continued to impact negatively on their daily lives. These negative impacts affected the majority of the pathway after the genesis of the complaint and could be experienced at most points of the journey through care. This finding resulted in a new addition to the map of the journey through care, which had multiple pathways to, from, and through it (Figure S4).

The negative impacts on everyday living occurred in the individual's personal relationships, job performance and social activities.

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)

The next quote shows the impact on an individual's working life where the pain disrupts his day-to-day functioning in his work.

Oh yeah, everything was a lot harder [because of the pain]. I mean it still is, even stood here now, it's a lot harder...I couldn't ignore it, you know. I did four months in Saudi and I was like getting up on the morning and oh god...It [the pain] was just like a nagging, aching...it can make you like bad-tempered (Pt 28)

The social consequences of other people knowing about the pain and the difficulties of obtaining a diagnosis could lead to a perceived lack of support. This could result in social handicap:

I think parents and parents-in-law were just kind of fed-up of this woman that was always in pain. Always in a corner, you know, at a party taking painkillers and drinking water rather than having fun. But it was very wearing (Pt 18)

Despite experiencing sometimes severe negative impacts from their illness, participants could be more concerned about diagnosis rather than the treatment possibilities.

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

Some participants had been seen at multiple centres and involved in cyclic referrals with resultant loss of personal legitimacy. They explained they experienced felt stigma as a 'malingerer'. One interviewee had been told explicitly that she 'was a timewaster who was just imagining it' (Pt 18)

And this particular registrar, which he was, came in, looked at my mouth, he said well nobody's bite's perfect. He said I think you're just grinding your teeth and you've got acute TMJD. You either stop grinding your teeth or I'm going to have to send you to see a psychologist and even wire your jaw. Well, I mean, when you were in the type of pain that I was in, I just...[tails off] (Pt 9)

All interviewees told of the emotional relief of eventually receiving a diagnosis that fitted their experiences and expressed liberation at knowing they were not 'the only one' (Pt 23) and therefore possessing a reference point.

And I think the reassurance was once it was almost like somebody [secondary care] had said to me hang on a minute, this is what we think it is. And as soon as I had sort of been given this name I did look on the Internet and I thought yeah that sounds like what I'm going through. And when I attended here [secondary care] and realised that there was other patients here with the same condition.

And speaking to people, I'm surprised at how many people I actually know who actually wear splints. I didn't realise...do you know what I mean (Pt 16)

As demonstrated in the quote above, the knowledge of the cause of their complaint and the possession of a reference point empowered the interviewees to ask more questions about the condition from both published sources and friends. These were self-initiated coping strategies simply brought about by diagnosis and an explanation that fitted with their experiences.

Experiences of secondary care could be grouped into two categories of outcomes. The first category was that the individual either implicitly or explicitly required further secondary care to manage their complaint; the other outcome was that the individual either implicitly or explicitly felt able to self-manage their illness. This resulted in two further pathways in the final map of the journey through care (Fig. 1).

Participants implicitly or explicitly associated several factors with the ability to self-manage their condition: their knowledge of the illness, its precipitators and its fluctuating course; their confidence in the clinician and their diagnosis; a reduction in their pain or dysfunction that they had been able to maintain by self-management.

Professor [name of dental consultant]...he told us what it was and he started like prodding about and rubbed me jaw and he knew straight away what it was (Pt 14)

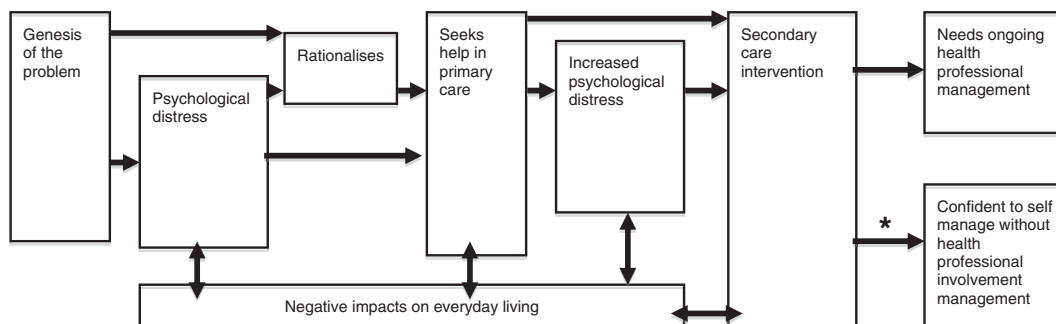
I'm told by the professional, no it's not that serious... he [dental consultant] filled us with confidence and he, like, I felt as if he knew

exactly what he was doing, what he was [doing], you know, and gives us confidence (Pt 23)

And that I can, you know, control it. Because as it is now, I know I do have bouts, but because I know what it is I'm not sort of...because I think what would happen is you would have the pain...because I've got it a little bit there now. I [used to] just think about it all the time whereas I forget about it [now]. And once you forget about it, it's not really as bad as what you think it was to begin with (Pt 13)

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

Those who reported a need for ongoing care described the following: difficulties accepting the diagnosis; symptoms suggestive of low self-efficacy; a lack of concordance between their expectations and clinical expectations for TMD management outcomes. Those who reported difficulties accepting a diagnosis and whose narrative suggested symptoms suggestive of low self-efficacy, such as lack of perceived control over the illness, were generally sufferers who had previously received multiple diagnoses and/or treatment. Patient 18 had six different consultations each with different diagnoses and treatments. Her account illustrates the doubt that can be left in the patient's mind at the end of a journey through care.



*- Influencing factors:

- 1) Reduction in pain or dysfunction
- 2) Knowledge of source of complaint (diagnosis) and understanding of illness (reference point and nature of illness)
- 3) Confidence in: clinician, diagnosis, personal ability to self manage the condition

Fig. 1. Final version of map of TMD patients' journey through care.

Well I still worry about it [the condition and its pain]. I still worry about it now because it's still with me. And even last night I'd be sitting there with the water and the painkillers. It hasn't gone away...and I still think that maybe...because maybe I should have the teeth out. Maybe it's still a dental problem. So no I still...I do, I do worry about it. And I worry about where it's going to go from here, as I get older and the problems become more acute...At one point I had a [pause] when I saw Mr [clinician's name and location], at one point I had a scan, a brain scan, to see if there was any abnormality. And I also had my, can't remember what they're called now, parotid ducts? Examined in case that was causing it. I also had an examination of my sinuses. So yes, yes. And I also, because of my [pause] I have a lot of middle ear problems, I was concerned about the fact that my hearing was deteriorating and I was terrified that it was all connected. In fact I'm still not convinced it's not...So, yes, of course. I mean I still worry about it. As you get older it's a worry about how where it's going to flare up again (Pt 18)

Discussion

These findings parallel aspects of other chronic conditions such as back pain, rheumatoid arthritis and systemic lupus erythematosus (19–21). The journey described here, and their effects, also parallels several established and accepted sociological theories (22–24).

The start of the journey is similar to that described by people with multiple sclerosis with either a sudden or insidious onset to their illness (25). The sudden onset appears to be a dramatic sign of a possible acute illness. In our data, this sign immediately legitimized the complaint to relatives and friends and gave the 'patient' the rights to decrease their daily social and work obligations and to receive support from friends and family (24).

Generally, those individuals who experienced a sudden onset of their complaint rationalized their complaint to a particular cause; they tended to do so within a context of their own, usually limited, knowledge of TMDs. Such individuals could attribute more sinister or serious origins to their complaint causing further psychological distress,

which could then be compounded by the lack of a definitive diagnosis.

An insidious onset of TMDs brought its own problems. Those affected know something is not quite 'right', but find it difficult to explain this to family and friends. They seek expert opinion in primary care but often find no real answers and their problem persists or worsens. This leaves them in an uncertain state between illness and health in the eyes of their immediate social network. The result can be a lack of support for their illness, leading to a struggle to maintain their normal commitments and personal roles in their lives. This is a finding mirrored in chronic back pain and other chronic musculoskeletal conditions; sufferers of chronic back pain have even been described as 'striving for the sick role' (19). Those suffering from chronic musculoskeletal problems share many of the same problems our sample describe in conducting their everyday lives (19, 21, 26–30). A large proportion of these problems are potentially caused by the 'ambiguity' of chronic pain through a lack of 'objective' evidence (31).

The only two other qualitative studies into TMD have also demonstrated TMD patients' difficulty in obtaining recognition that they have a verifiable illness (32, 33), but neither of these two studies investigated the problems patients have with obtaining legitimacy for their complaint or with the pathway through care. The pathway through care illustrated by this study highlights that improving the communication between the professional and the patient may be the key to decreasing psychological distress over the cause of the complaint and helping the patient enlist social support. The professional may be in a position to (i) exclude sinister pathology; (ii) explain their provisional benign diagnosis of muscular, joint, or disc problem prior to referral; (iii) acknowledge and recognize any pain or disability associated with the complaint and therefore give the patient legitimacy for their complaint.

An ongoing search for a diagnosis, principally in primary care, seems to enhance a belief that their problem might be considered psychosomatic. Ill-chosen words from health care professionals can serve to increase this felt stigma (23). Individuals may then start to hide their illness and its symptoms from relatives whilst still experiencing disruption in their lives from the illness. The ongoing 'hidden' symptoms led some interviewees to report experiences that could be likened to experiencing a 'loss of self' (22): discreditation, social isolation, restriction

of day-to-day activities, feeling burdensome, all of which can worsen their pre-existing complaint.

It is possible for this loss of self and biographical disruption (34) to be perpetuated by misdiagnosis, negative labelling and/or inappropriate treatment. The disruption only stops, and reconstruction of self begins, once a clear diagnosis is given and the sufferer has confidence in both the diagnosis and the clinician.

The clinical management of the illness reported by the sufferers seems to be based, unintentionally, on some of the five skills of self-management (35): (i) problem-solving; (ii) decision-making; (iii) resource utilization; (iv) forming health care partnerships; and (v) taking action. Within the context of this research, sufferers of TMDs who are able to self-manage their condition have formed a partnership with a clinician, had their problems identified for them, been shown how to utilize strategies to deal with their problems and are therefore able to make informed decisions about those problems.

The potential function of self-management (35) in TMDs is one of the key clinical applications of this piece of research. The other potential application of the pathway through care is in identifying point(s) during individual's journey through care where intervention might be most beneficial. Our results would suggest that if individuals received an early diagnosis in primary care, then a large amount of the health care burden TMDs place on secondary care might be reduced. Standardized, reversible, conservative therapy instituted in primary care might also help reduce the negative impacts of the illness on the individual and help them establish a degree of perceived control over the complaint. Further work is required to identify any possible behavioural intervention that would influence primary care practitioners to perform in this manner.

TMDs as a group of chronic illnesses affecting the mouth and jaws mirror the wider chronic illness literature, with the potential for useful management tools that lie outside of the dental literature. The map of the journey through care demonstrates the potential for interaction between the stages of the journey and the illness itself. In so doing, the points at which interventions may be possible to help minimize the far-reaching effects of the illness and the journey can be identified. Early provisional diagnosis and explanation of TMDs at the initial point of contact have the potential to reduce the overall burden of care on the patient

and service. The possession of this diagnostic reference point may help the initiation of self-coping strategies and the effects of the illness.

Further research is required to quantify how representative this pathway is for patients with TMD in the United Kingdom and other countries and some would also suggest that the pathway is taken back to the (same) patients for triangulation/validation but that this need is tempered by the use of more than one researcher analysing the data in this study (36). Work is underway to investigate what type of behavioural intervention is required to help primary care practitioners make a diagnosis of TMDs and begin initial management.

In conclusion, the pathway reported by the sample exerts negative impacts on the patient. It appears possible to reduce these impacts by the early assertion of a provisional diagnosis. The provision of a defined, centralized and specialist orofacial pain service in secondary care might help reduce the cyclical referral possibilities in secondary care, which can compound the difficulties the patient has already experienced in primary care. A named service might also help primary care practitioners who simply wanted to discuss cases.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Patient 18's 'plotted' journey through care.

Figure S1. Basic three stages of temporomandibular disorder patients journey through care.

Figure S2. Basic three stages and first direct experience after genesis of the problem.

Figure S3. Basic three stages and direct experiences after genesis and primary care.

Figure S4. Addition of the underpinning negative impacts on everyday living.

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