A report for RDSYH patient and public and involvement to review a proposal for alteration in the delivery of care for temporomandibular joint pain

Investigators

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Dr S Harrison has responsibility for mentoring and supporting the PPI providing advice to the research team
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Introduction

Temporomandibular joint disorder (TMD) has been defined as an aggregate of clinical problems that involve the craniofacial muscles, the temporomandibular joint and associated structures (1). Large postal surveys suggest a 5-15% incidence of symptomatic TMD in the general population (2-3) but the prevalence is higher in some professional groups such as nurses (57%) and students (26%) (4-5). In Sweden it has been estimated that 3-7% of the population seek medical help for TMD related symptoms (6). Numerous studies have clearly demonstrated that TMD pain significantly impacts on the patient’s quality of life (7). For some patients the symptoms are mild; whilst others have severe disabling pain that inhibits normal daily activities including the ability to work. In the USA it is estimated that 17,800,000 days are lost each year for every 100,000,000 working adults due to disabling TMD (8). Clearly TMD has a significant impact on both society and valuable health resources.

The National Institute of Health (1996) stated that the vast majority of TMD patients should be managed using non-invasive and reversible therapies; and irreversible treatments such as surgery avoided if possible (9). Studies have shown that >85% of patients obtain pain relief with conservative treatment and few require surgery (10-11).

Patients with TMD are initially diagnosed and managed by general dental (and medical) practitioners, but if symptoms persist patients are subsequently referred to a hospital consultant. Within secondary care patients with TMD add to waiting lists and use valuable hospital resources. Some Primary Care Trusts (PCT) in England, have already attempted to reduce the number patients with TMD referred to hospital including one of the PCTs local to the site of this proposed study. Whilst this policy may have short term gains for the NHS economy, the suffering of the patient and subsequent impact on NHS services has been ignored. In Sheffield we find that despite the PCT recommendations, patients with TMD are still referred but are sent under the aegis of ‘undiagnosed pain’ or ‘pain requiring surgical intervention’. We propose to evaluate a service alteration that will be both clinically effective but cost-beneficial for patients with TMD.

Physiotherapy interventions including education reduce pain and improve function in patients with TMD (12-13). Physiotherapists are also able to offer psychological interventions that are beneficial to patients with chronic musculoskeletal pain (14-15). In parts of Europe (i.e. Netherlands) patients with TMD are frequently referred directly to physiotherapists by dentists. However here in the UK, dentists are unable to access NHS physiotherapy services and consequently within the NHS patients are referred directly to hospital.

The benefit of employing physiotherapy-led clinics at the interface between primary and secondary care has been established in orthopaedics and neurosurgery (ref). Within these clinics the physiotherapist role is to act as a gate keeper ensuring that alternative treatments are explored before patients are referred to hospital consultants. In orthopaedics the introduction of a physiotherapy-led clinic resulted in fewer and more appropriate referrals to consultants (16) and an improvement in quality of life for patients (17). Moreover studies have revealed that patients are more satisfied with physiotherapy-led treatment than direct referral to a surgeon (17). The extension of the physiotherapy-led clinics to help manage patients with TMD is therefore a natural progression of an already successful service development.
Another major advantage of physiotherapy-led services is that they allow patient rapid access to care and avoiding long waiting times. This is important because the early treatment of acute TMD results in greater patient satisfaction, the loss of fewer working days, and a reduced chance of the development of a chronic and intransigent pain (18).

However it is essential that a physiotherapy-led service for patients with TMD is evaluated prior to widespread introduction in the NHS. Facial pain has multiple diverse aetiologies and it is widely acknowledged that interpreting clinical signs and symptoms in patients with facial pain can be difficult. Currently patients referred to a physiotherapist have been treatment planned by hospital consultants and physiotherapists do not normally diagnose different types of facial pain and formulate treatment plans. Therefore one of the key questions to be determined is ‘Can an adequately trained, supervised and supported physiotherapist-led service effectively manage patients with TMD, and importantly are they able to triage patients correctly and identify those patients requiring referral to a hospital consultant?'

It is increasingly important in all aspects of health science research involve patient or ‘public advisors’. It is important for commissioners of services to know that the patients and public have been involved in studies that have evaluated the clinical and cost-effectiveness of services. Therefore patients with TMD are central to this study.
Methods

Patients forming the PPI were recruited directly from both A R Loescher and S D Harrisons clinics. A total of twelve patients have been recruited but as two have left we have ten current advisors. All had suffered with temporomandibular joint pain for a period of time and several undergone physiotherapy as part of their treatment.

Initially a meeting was held on 8.9.10 at the School of Clinical Dentistry 5.00pm a time thought to be mutually convenient to many of our patient advisors. Although ten patients were invited only 3 actually attended with subsequent excuses from many others. The meeting was hosted by both S D Harrison and A R Loescher

The format of the meeting was

a) Welcome and Introductions  
b) Explanation of current treatment of TMD patients  
c) Proposed trail  
d) Discussion

To improve our feedback a postal questionnaire (see attached) was sent to ten public advisors but feedback was still deemed unsatisfactory (6 out of 10 patients responded)

Therefore with the help of technical support from the University of Sheffield a secure internet virtual forum has been established. We are now able to answer specific questions about our study and have dialogue without the public advisors travelling to Sheffield.

The questions that have been asked to date include

1) Is the project summary easily understood by a lay reader?  
2) As patients with facial pain are they happy to wait 18 weeks to be seen by a hospital consultant?  
3) If asked to take part in our proposed study would they be happy to do so knowing that they may not be seen by a consultant?  
4) If the answer to question 3 is ‘no’ would you be willing to wait to be seen by a consultant?
This virtual forum (via a secure internet site) of people with TMD will advise the research team on issues relating to patient and public involvement throughout the conduct of the study. Two members of the virtual forum will be invited onto the Trial Steering Committee and Trial Management Committee to scrutinise the conduct of the research, ensure that resources are used appropriately and to monitor progress. The people with TMD will be asked to provide advice to the research team on

- The lay summary of the application to the Research Ethics Committee
- The design and content of the study recruitment letter, patient information sheet and consent form
- Any training of personnel undertaking the research
- Involvement in interpreting the analysis of the qualitative data, reporting and study dissemination

A member of the research team (SH) will provide mentoring and support for the people with TMD who will be providing advice to the research team. A glossary of key terms used in the research will be offered, and payment for time and out of pocket expenses will be provided to those people with TMD who will be members of the Trial Steering Committee and Trial Management Committee. Best practice guidance on public involvement in research as set out by INVOLVE will be followed.

**Grant submission and outcome.**
A grant was submitted to the RfPB entitled ‘A study to determine the feasibility of primary care physiotherapists employing CBT to manage patients with TMD’. This application was unsuccessful. After reading the referees reports and in conjunction with colleagues the project has been significantly revised and simplified. In June it was submitted to the SDO programme ‘A pilot study to determine the feasibility of employing an interface physiotherapy-led service to manage patient with temporomandibular joint disorder rather than direct referral to a hospital consultant’. We are awaiting a decision.

**Account of costings.**

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References