Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders

A dissertation submitted for the degree of Doctor of Philosophy of the University of Dublin, Trinity College, Dublin 2.

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Declaration

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Summary

Temporomandibular disorders (TMDs) develop as a result of alterations in the structure/function of the temporomandibular joint (TMJ), masticatory muscles, and/or osseous components. TMDs may be caused by both non-inflammatory (e.g.: myalgia) and inflammatory disorders (e.g.: rheumatoid arthritis (RA)). Common signs and symptoms of TMDs include: TMJ pain, dysfunction, fatigue, and limited ranges of motion. These issues impact on oral functions such as mastication, with potential implications for overall eating and possibly swallowing. However, there has been limited research on this topic, with the potential for restricted care provision. Based on the Student's clinical and personal experience of a TMD, and from the available literature, it is hypothesised that eating and potentially swallowing problems are prevalent in adults with TMDs and that intervention related to eating and swallowing may be limited. The aim of this research was to determine the epidemiology, nature, impact, and management of eating and swallowing difficulties in adults with TMDs caused by a range of non-inflammatory and inflammatory conditions, to provide information on these problems, and to suggest avenues for future research and clinical developments.

To explore the epidemiology, nature, and impact of these problems, systematic reviews with meta-analyses were conducted, informing the design of two cross-sectional prospective patient studies. Treatment-seeking adults with TMDs presenting to national specialist care centres were recruited for these studies, with data collected using both established subjective and investigator reported outcome measures (IROM) and newly designed cohort-specific assessments. In addition, the typical management of eating and swallowing issues in this group was investigated by surveying professional and patient perspectives on, and satisfaction with, typical care delivery for patients with both non-inflammatory and inflammatory TMDs in Ireland. Descriptive and statistical analyses were conducted.

Results of the studies conducted within this thesis confirm that eating and swallowing difficulties are commonly reported by this group, with 99% of treatment-seeking adults with TMDs reporting at least one such symptom, with reported repercussions on nutrition, activity, participation, and emotional well-being. As hypothesised, masticatory difficulties were reported most frequently (89%), yet 53% of participants also reported additional swallowing difficulties such as: choking on medication (45%), or experiencing a 'strangling sensation' on swallowing (48%). Patients with TMDs reported that these eating and swallowing difficulties impact moderately on daily, social, recreational, and family activities, with a mild impact on their ability to work and their occupational productivity. Patients with TMDs associated with RA reported higher rates of oropharyngeal swallowing difficulties than those with non-inflammatory conditions, suggesting the need for specifically targeted management programs, although limited numbers of participants with RA were recruited here.

The combination of limited available research or education and the complex profile of patients with TMDs may contribute to reduced professional awareness of eating and swallowing difficulties

in this group. Surveyed oral surgeons, oral and maxillofacial surgeons, oral medicine and pain consultants, prosthodontists, and rheumatologists reported limited clinical experience in the management of TMD-related eating and swallowing difficulties. Of the respondents who do currently assess for eating and swallowing during TMD care provision, the majority were dissatisfied with available assessment tools and reported the need for contemporaneous resources (52%). This research addressed these issues by developing both a structured interview tool and an assessment protocol for use with thus patient group which incorporates IROM and subjective instruments from a range of healthcare disciplines.

As well as assessment challenges, 53% of these surveyed clinicians reported dissatisfaction in treating eating and swallowing problems in patients with TMDs as they must use non-cohort-specific and non-evidence-based interventions due to the lack of available resources. Although 37% of clinicians stated that they provide patients with education on eating and swallowing problems, patients with TMDs in the prospective study reported additional information needs on the prevention and management of these difficulties. To address these patient concerns, an educational booklet on eating and swallowing problems in adults with TMDs was developed and piloted here, which is suitable for future clinical dissemination.

As with all research there are limitations. For example, only treatment-seeking patients presenting to specialist centers of care were recruited throughout the prospective studies, and fewer clinicians than anticipated participated in the surveys of professional perspectives. Despite this, these findings have generated new information on eating and swallowing problems in adults with TMDs. There are recommendations for future research and clinical practice, which include: 1) the validation, refinement, and dissemination of the new assessments and educational resources designed and piloted during this research; 2) further epidemiological research of eating and swallowing difficulties in a broad spectrum of both treatment-seeking and non-treatment-seeking adults; 3) further research on the potential differences in eating and swallowing difficulties between adults presenting with inflammatory and non-inflammatory TMDs; 4) the use of this data to inform research and development of cohort-specific evidence-based treatments and cost-effective models of service delivery to improve care provision; and 5) the integration of professionals with specialist skills in the clinical management of eating, swallowing, and nutritional difficulties into future TMD multi-disciplinary teams (e.g.: speech and language therapists and dietitians).

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Section One

Section One of this dissertation introduces eating and swallowing problems in adults with temporomandibular disorders, presents the theoretical framework which guided this research, and concludes with a discussion of research aims and questions.

Chapter One: Literature Review

1.0. Introduction

In this literature review, the main arguments relating to the epidemiology, nature, impact, and management of eating and swallowing difficulties caused by temporomandibular disorders (TMDs) will be discussed. This chapter presents: 1) an overview of the anatomy and physiology of the temporomandibular joint (TMJ); 2) an outline of potential risk factors for TMD development and typical TMD symptom profiles; 3) a discussion of the epidemiology, nature, and impact of eating and swallowing problems in adults with TMDs; 4) a synopsis of clinical and research challenges within this field; and 5) an exploration of the potential impact of these challenges on service delivery and the patient's experience of care.

1.1. Typical Anatomy and Physiology of the Temporomandibular Joint and the Potential for the Development of Dysfunction

The TMJ is a non-weight bearing joint internally composed of the articular capsule, the cartilaginous disc, and the synovial membrane(1–3), drawing external support from dentition, accessory ligaments, and masticatory muscles(4,5). The TMJ works with these ancillary components to coordinate the complex tasks of articulation, mastication, deglutition, and respiration, all of which are integral to nutrition and communication(6). Articulations between the condyle, the articular eminence, and the mandibular fossa form the outer boundaries of the TMJ(7) (see Figure 1). While the appearance of these articulating surfaces are variable due to developmental differences, osseous remodelling secondary to malocclusion or trauma can occur, resulting in the development of TMDs. Research has established that these conditions can cause alterations in bite, reduced mandibular range of motion (ROM), and impaired mastication(5,8). However, it is hypothesised here that these oral stage difficulties may also have repercussions for eating and possibly swallowing, although research on this topic is currently limited.

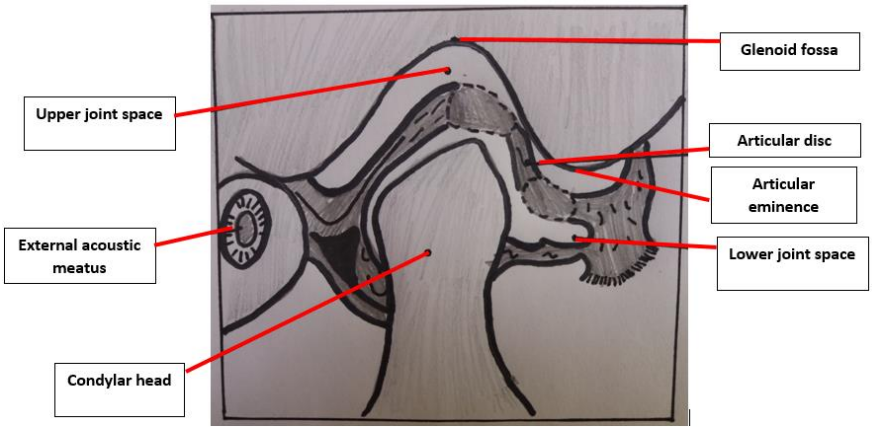


Figure 1: The TMJ Complex

Typically, the articulating surfaces do not contact one another and are separated by the articular disc(7). The articular disc is a fibrous bio-concave structure positioned between the squamous section of the temporal bone and the condylar head of the mandible(1). It moves passively between the articulating surfaces during jaw functioning, maximising surface contact, distributing stress, and minimizing localised damage and bone contact(1,8–12) (see Figure 2). If disc functioning and/or positioning is obstructed, bone erosion can develop due to disc compression, tension, or shearing, with potential for the development of disc displacements (DDs) and TMDs(3,13). DDs, both with and without reduction, are associated with joint sounds, pain, reduced ROM, and TMJ locking, all of which may impact on eating and possibly swallowing.

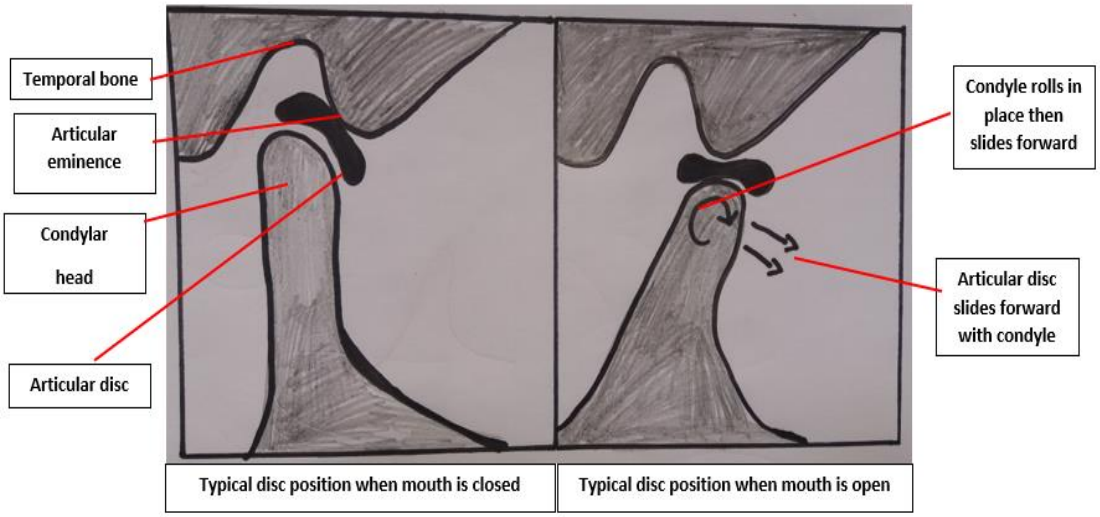


Figure 2: Typical Movements of the Articular Disc

Supporting the TMJ are elevator and depressor muscles which facilitate jaw functioning, with support from accessory muscles and ligaments(2,8,10) (see Figure 3). These muscles extend from the cranium, ultimately inserting into the mandible and TMJ complex(8). Muscular contractures due to developmental variations, trauma, and/or parafunctional habits can result in microstomia, pain, and fatigue, with potential impact on endurance for meals and oral intake, although research is limited.

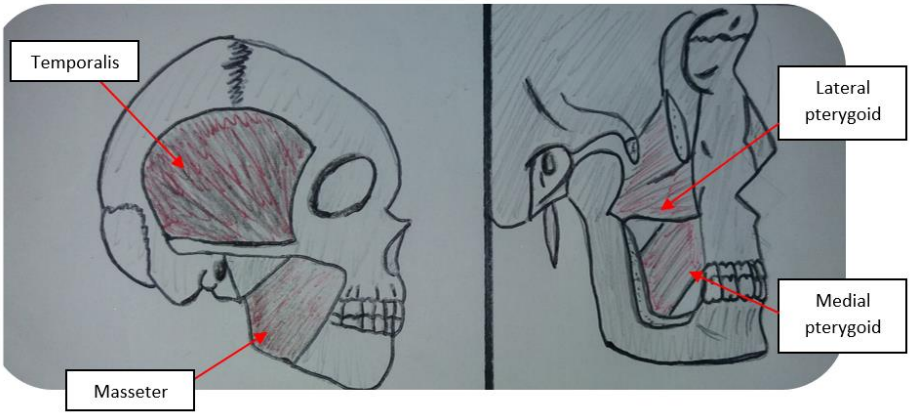


Figure 3: Muscles of Mastication

The cranial nerves which supply motoric and sensorial fibres to these muscles include: the facial, glossopharyngeal, and hypoglossal nerves, with support from the sensory, motor, and premotor nuclei of the trigeminal nerve(14). Neurological damage to these cranial nerves can result in limited ROM, sensory impairments, and neuralgia, which have the potential to impact negatively on mastication, with hypothesised consequences for eating, swallowing, and health-related quality of life (HRQOL).

1.2. The Epidemiology, Nature, and Impact of Temporomandibular Disorders

As the TMJ facilitates many complex movements, changes to its structure and/or function may impact on the completion of a range of activities of daily living (ADLs)(15). Although researchers have historically faced difficulties in the provision of a universally accepted definition for TMDs(16–21), the criteria which will be adopted in this research is: a range of heterogeneous conditions characterised by pain and dysfunction of the TMJ complex, due to alterations in the structure and/or function of the uni- or bilateral TMJ, the wider masticatory muscle system, and/or the osseous components(16,22–24). This definition reflects the complexity of TMDs, with focus on: the heterogeneity of potential signs and symptoms(22,25,26), the common experience of dysfunction across multiple loci within the TMJ complex, and the frequent secondary dysfunction in contiguous/non-contiguous head and neck structures, the upper quadrant, the central nervous and/or musculoskeletal system(16,22,25,27–31). The most common categories of TMJ symptoms are: DDs with reduction (DDWR), DDs without reduction (DDWOR), degenerative joint disorder (DJD), and subluxation(15). The most frequent masticatory muscle disorders are: myalgia, myofascial pain (MFP), arthralgia, and headache attributed to TMD(15) (see Figure 4). Overall, TMDs are the most frequently experienced orofacial pain conditions of non-dental origin, and the second most common musculoskeletal and neuromuscular disorders after lower back pain(32–35). Research suggests that up to 93% of the general population experience at least one TMD symptom at some point during their lifespan, while 10-20% of these individuals seek treatment for these difficulties (27,32,34).

TMDs have an established impact on social, economic, and healthcare structures(22). Research has documented decreased levels of HRQOL, socialisation, and social networks(36,37), in conjunction with increased depression among patients with TMDs(38,39). At an economic level, patients with TMDs report reduced ability to obtain and maintain occupational roles(36,37,40), in conjunction with increased medicolegal and insurance claims, and greater use of TMD-specific and non-TMD-specific healthcare services(41–43). TMDs cost North American patients between $12,000 and $20,000 dollars per annum(44), while costing the overall economy up to $4 billion annually(45). Irish figures on the economic impact of TMDs are currently unavailable. In light of these individual and societal ramifications, greater understanding of these conditions is needed to improve management, clinical outcomes, and patient well-being.

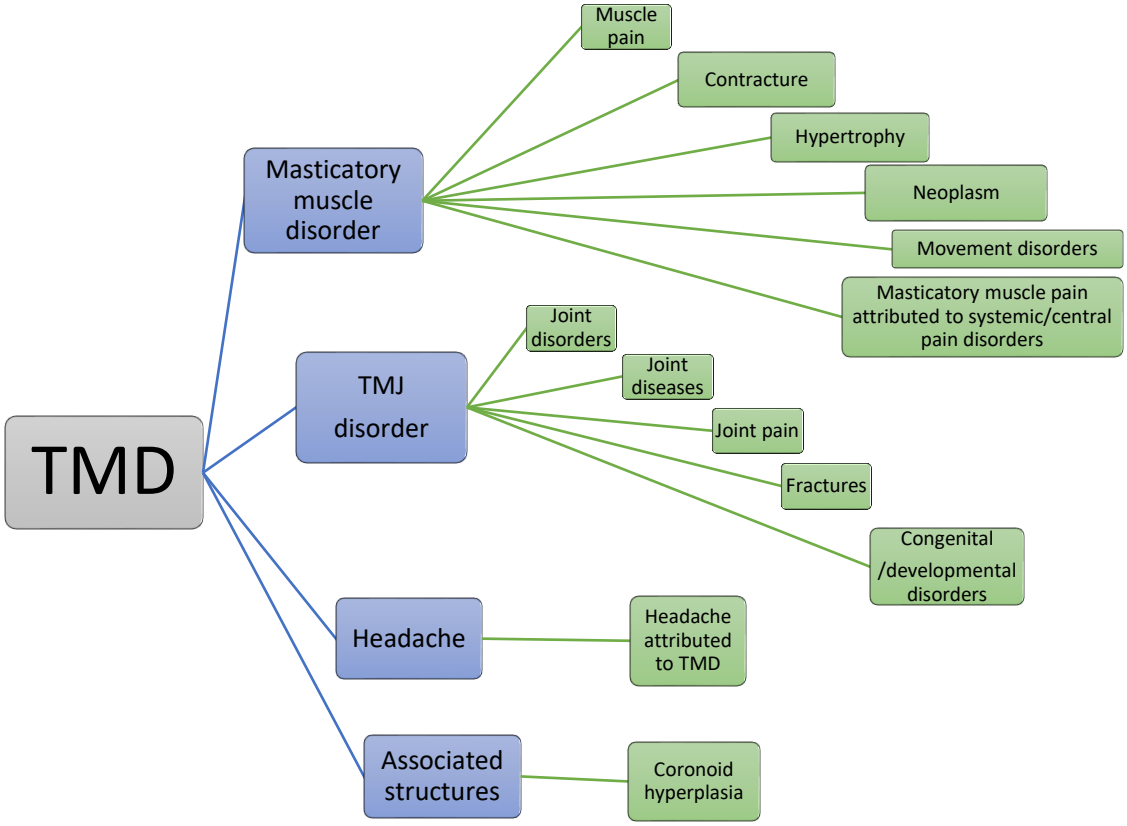


Figure 4: Symptomatic Subcategories of Temporomandibular Disorders

1.2.1. Risk Factors for the Development of Temporomandibular Disorders

Risk factors for the development of TMDs are contentious, with research investigating several themes over the previous 8 decades (see Figure 5 and Table 1). However, to date, no definitive links have been established between the presence of a single risk factor and the subsequent development of TMDs(27,46). Recent investigations have emphasized the probability of a multifactorial aetiology, encompassing psychological, physiological, structural, and postural factors which disrupt the balance between the muscles of mastication, occlusion, and the TMJ complex and impair typical stomatognathic functioning(27,47). These factors are conceptualised as: predisposing (e.g.: structural, endocrine, and/or psychological issues which may impact on stomatognathic functioning and increase the risk of TMD development), precipitating (e.g.: micro- and/or macro-trauma), and perpetuating factors (e.g.: parafunctional habits, hormonal, and/or psychosocial factors) which may contribute to TMD development and chronicity, although further research is required to confirm this hypothesis.

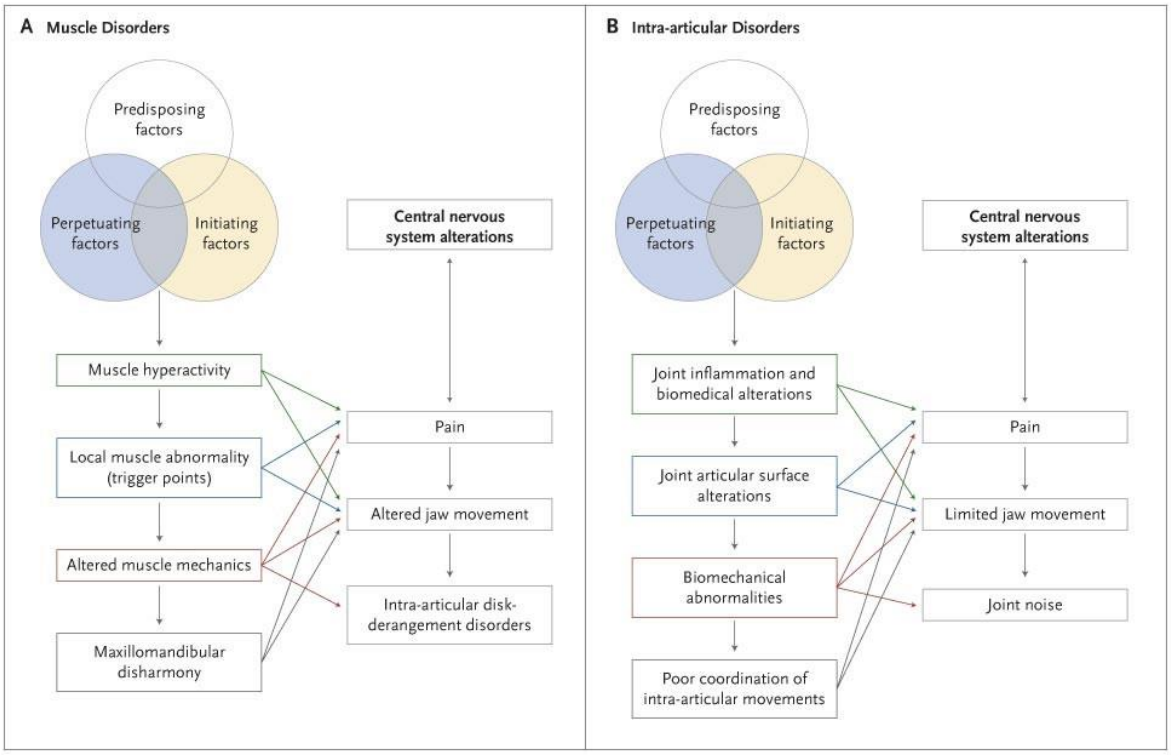


Figure 5: Theory of Multi-factorial Origin of Temporomandibular Disorders (Reprinted from: "Temporomandibular disorders" by S. J., Scrivani, Keith, D. A., & Kaban, L. B. (2008). New England Journal of Medicine, 359(25), 2693-2705.239 Copyright [2008] by the New England Journal of Medicine.(48) Reprinted with permission.)

As risk factors for the development of general TMD signs and symptoms (e.g.: TMJ pain and fatigue or impaired mastication) are still unclear, it is unknown which factors potentially introduce the greatest risk of developing subsequent eating and/or swallowing problems. However, it is hypothesised that individuals presenting with inflammatory conditions such as rheumatoid arthritis (RA) may be at a greater risk of developing these problems than those with non-inflammatory conditions. This is hypothesised to be due to the inflammatory disease processes, impact on functioning, and concomitant psychosocial distress associated with RA. This will be explored in greater detail in the subsequent section.

Table 1: Research on Potential Risk Factors for TMD Development

Risk factor	Key findings of research conducted
Chronological age	• 2 Gaussian curve peaks of TMD prevalence at 32.7 and 54.2 years of age(25) • No significant associations between TMJ morphological changes, severity of subjective symptoms, or objective impairments in functional movement patterns and increasing age (49–51)
Gender	• Large female representation within treatment-seeking patients with TMDs (female:male ratio range = 2:1 to 9:1)(47,52) • Significant female gender effect on the prevalence and perceived severity of TMD signs and symptoms (32,47,53,54) • Oestrogen receptors may modulate ligament laxity while altering typical limbic system activity, thus increasing vigilance for, perception of, and treatment-seeking in response to pain stimuli among females(32) • Habitual orofacial behaviours are influenced by gender and directly influence the frequency and severity of TMDs(55,56) • Females may experience greater levels of depression, stress, and anxiety, which contribute to the predisposition, precipitation, and perpetuation, of TMDs and influence treatment outcomes(55,56) • Females demonstrate lower self-efficacy and higher levels of pain responsivity and catastrophizing, which are associated with increased levels of pain and pain-related disability(56–58)
Occlusion	• No significant association between specific types of malocclusion and TMD pathogenesis has been found(59)
Oral and maxillofacial trauma	• Sporadic links have been found between physiological reactions to childhood intra-capsular condylar trauma and subsequent development of ankylosis(60–62), yet correlations between other types of fractures and the development of TMDs are contentious(63,64)
Parafunctional behaviours	• No definitive associations have been documented, with the degree of detected links between parafunction and TMD development declining as the rigour of primary studies increase(65)
Psychosocial functioning	• Differences have been identified in psychological parameters between individuals with TMDs and healthy matched controls (25,56,66–69), even with adjustment for sex, age, demographics, and health behaviours(56,70) • Although the experience of pain acts as a stressor and negatively impacts on coping, some studies have detected no significant differences between patients presenting with TMDs and healthy controls in this domain(67,71) • There have been no conclusive findings of a specific "TMD-type" personality(72), and controversy relates to whether emotional, cognitive, and psychosocial difficulties predispose/precipitate TMD development, or whether these difficulties are elevated in response to attempts to live in a satisfactory manner despite chronic pain and dysfunction(73–79).

Central sensitization	• A range of findings which may be indicative of central sensitization have been found in individuals with TMDs, e.g.:
	  ○ Enhanced temporal summation and temporal integration of thermal pain(80);
	  ○ Increased sensitivity to both pleasant and unpleasant stimuli;
	  ○ Decreased tolerance to environmental stimuli;
	  ○ Increased levels of pain sensitivity within specific orofacial and extra-cranial regions subsequent to orofacial isometric contractions(81);
	  ○ Increased pain sensitivity and severity within remote axial sites in which no clinical pain had been reported on presentation(82–86);
	  ○ Increased whole body widespread mechanical and thermal pain sensitivity(87);
	  ○ Higher levels and areas of pain referral (80,82–84,88,89); and
	  ○ Decreased bilateral pain pressure thresholds in TMJ, facial, cranial, and axial locations(82,90)
	• However, there is yet no conclusive evidence that central sensitisation is a definitive aetiological factor in the development of TMDs(91)

1.2.2. The Risk of Temporomandibular Disorders in People with Rheumatoid Arthritis

RA is a multi-system autoimmune disorder of unknown aetiology affecting the systemic health of 1-3% of adults globally(92,93). It is one of the leading global causes of progressive disability and is associated with body-wide functional and physiological implications, reduced HRQOL, socioeconomic burdens, and increased patient morbidity and mortality(92–95). RA is characterised by progressive remissions and exacerbations of immune-mediated, polyarticular inflammation of symmetrical synovial joints, hyperplastic antibody production, and joint effusion(96–98). Although RA typically affects small diarthrodial joints(99), the TMJ is also affected in up to 93% of patients, which can result in the development of TMDs(100–104). Signs of the impact of RA on the TMJ include: inflamed synovium, reduced upper joint space, and degenerative changes to the articular disc. Symptoms include: joint sounds (e.g.: crepitation, clicks, and pops), myalgia of the supporting musculature, restricted and painful mandibular movements, and impaired mastication(98,105,106) (see Figure 6).

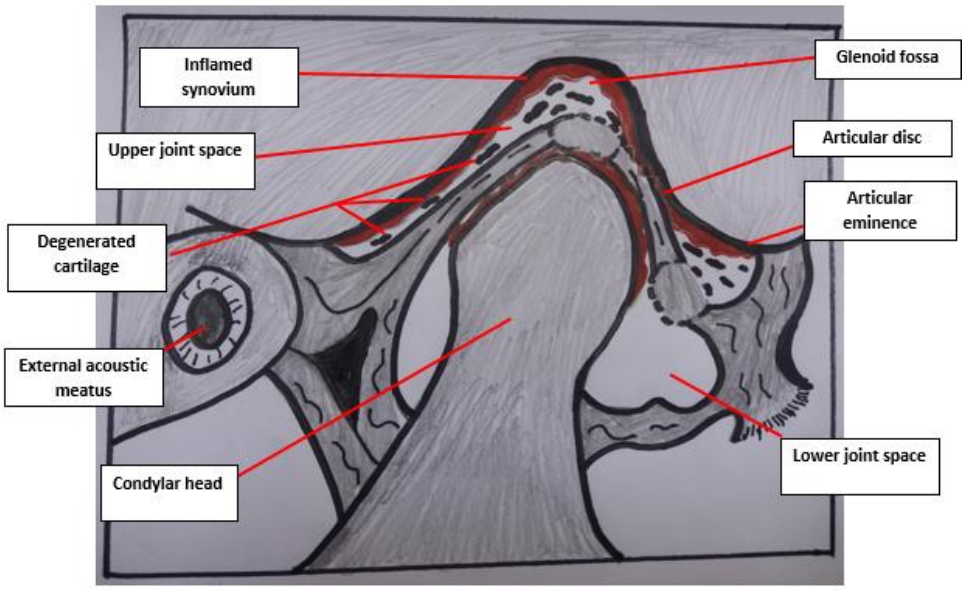


Figure 6: The Impact of RA on the TMJ Complex

Bony TMJ destruction begins early in the RA disease process and can be objectively detected at 6 months post-onset(105), with the most frequent radiographic findings at 5 to 10 years post-onset including: erosion, flattening, and resorption of the mandibular condyle(107–109). If untreated, this can progress to joint destruction and/or ankylosis(110,111), requiring joint replacement in severe cases. Therefore, these inflammatory changes may put the individual with RA at a higher risk of developing TMDs than patients with non-inflammatory conditions. It is established that these inflammatory processes impair mastication, and it is hypothesised here that masticatory difficulties may cause subsequent eating and possibly swallowing issues as the individual tries to swallow large, un-masticated boluses.

However, research in this field and understanding of the potential for the development of eating and swallowing problems is low. Therefore, clinical management may be limited and patients may subsequently experience reduced activity, participation, and HRQOL. As such, it is recommended that research investigates eating and swallowing problems in adults with TMDs to inform the need for improvements in care provision. This topic will now be explored in greater detail in subsequent sections.

1.3. Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Adults with TMDs frequently report impaired mastication and masticatory pain and fatigue due to joint and/or muscular dysfunction (32). These issues impact on chewing and bolus formation, and can result in the patient consuming soft or pureed diets, either independently or on the recommendation of a clinician. While it is established that these oral preparatory difficulties are common among adults with TMDs, little is known about their potential repercussions on the subsequent oropharyngeal stage of swallowing. It is hypothesised here that patients with TMDs may experience associated oral and oropharyngeal transit difficulties as a direct result of masticatory impairments. However, these patients may not experience inadequate airway protection, laryngotracheal penetration, or resultant aspiration pneumonia, and therefore may have no need for immediate medical care or hospitalisation. As such, these complex patient profiles combined with limited available research may suggest to clinicians and researchers that there is no need to address eating and swallowing concerns in adults with TMDs.

Yet, despite these perceptions, there are suggestions that patients with TMDs may be living with additional hidden eating and swallowing difficulties. For example: these experiences have been discussed by patients themselves via the use of online blogs and message forums (see Section 1.3.1). In addition, the Researcher here also has personal experience of TMD-related eating and swallowing issues. The Researcher experienced impaired mastication characterised by pain and fatigue. These chewing difficulties resulted in attempts to swallow larger boluses, with impact on oropharyngeal transit and subsequent choking experiences. However, clinical rehabilitation of these issues was not available, resulting in the development of symptom chronicity. These narrative accounts suggest that patients with TMDs may require specialist intervention to address these concerns (e.g.: masticatory rehabilitation, volume control techniques, liquid washdowns, or multiple and effortful swallows to effectively clear solid boluses). Therefore, further research is warranted to investigate the potential impact of impaired mastication in patients with TMDs on eating and swallowing.

1.3.1. The Epidemiology, Nature, and Impact of Eating and Swallowing Problems in Adults with Non-Inflammatory Temporomandibular Disorders

The epidemiology, nature, and impact of masticatory issues (e.g.: impaired motion, pain, and fatigue) in adults with non-inflammatory TMDs will now be discussed. In addition, the potential for

subsequent non-masticatory difficulties (e.g.: choking or gagging responses during deglutition with resultant altered oral intake and unintentional weight changes) will be also explored.

Impaired Mastication

Effective and efficient mastication has a vital role in overall digestion(112), with masticatory impairments potentially resulting in subsequent deficits in overall systemic health(113). As discussed, impaired mastication can result in the need to modify one's oral intake, with potential nutritional and gastrointestinal impact. As feeding and eating typically occurs within a social context, impaired chewing also introduces the potential for anxiety, embarrassment, and negative stigma, all of which may incur personal and social costs. In addition, the individual may need to purchase speciality soft or pureed foods, or foods enriched with additional calories or nutrients, with subsequent financial implications. However, in addition to these established difficulties, it is hypothesised here that impaired mastication may have further consequences for overall eating and swallowing, therefore warranting research to inform future care provision.

While high rates of impaired mastication in adults with TMDs have been reported(114–119), results are inconsistent (see Table 2).

Table 2: Studies reporting on the Prevalence of Impaired Mastication

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Radke et al.,(115)	2014	Unclear	Descriptive observational	28	1:1	34.5 (+-14.0)	100%
Maffei et al.,(114)	2012	Unclear	Descriptive observational	10	1.5:1	Unclear	90%
Reißmann et al.,(116)	2007	University clinic	Case-control	312	3.16:1	38.6 (+- 15.6)	82.07%
Barros et al.,(119)	2008	University clinic	Cross-sectional	132	4.92:1	36.5 (+-13.5)	80%
Mapelli et al.,(118)	2016	University clinic	Case-control	30	9:1	30.5 (unclear)	77%
Abrahamsson (117)	2013	University hospital clinic	Case-control	90	1.37:1	22 (+- 7.4)	75.2%
Wanman(120)	2012	University clinic	Case-control	108	5.23:1	40 (+-13)	62.95%
Brandini et al.,(121)	2011	Unspecified hospital	Case-control	15	15:0	31.3 (+-10.8)	60%
Khawaja et al.,(122)	2015	University clinic	Descriptive observational	94	1.47:1	34.2 (+-12.2)	56.38%
Foteder et al.,(123)	2015	University hospital clinic	Cross-sectional	195	5.91:1	34.8 (+- 17.2)	54.32%
Raphael & Marbach(124)	2001	University clinic and general dental practice	Randomised control trial (RCT)	63	1:0	33.7 (+-10.9)	49.2%
Ferreira et al., (125)	2017	Specialized private practice facial pain clinic and university hospital clinic	Case-control	12	12:0	37 (+-16)	41.66%
Baker et al.,(126)	2015	University clinic	RCT	34	10.3:1	38.9 (+- 15)	20.58%
Da Silva et al.,(127)	2011	University clinic	Case-control	70	0.84:1	53 (unclear)	11.1%
Gonçalves et al.,(128)	2011	University hospital clinic	Case-control	28	28:0	Unclear	0%
De Felicio et al., (129)	2012a	University clinic	Case-control	30	1:0	30 (+-8)	0%

Differences in estimates may relate to: the use of subjective (e.g.: paper-based questionnaires) or static Investigator Reported Outcome Measures (IROM) (e.g.: magnetic resonance imaging (MRI) or X-ray), with few studies using functional chewing tasks to dynamically assess

mastication(120,121,128); heterogeneity among participants which may skew prevalence figures; and the involvement of a range of professionals with a spectrum of clinical and educational backgrounds in the assessment of mastication. It is hypothesised that if impaired mastication is not addressed during TMD management, there may be ramifications for later stages of swallowing, with overall negative impact on nutrition and well-being. This may lead to poor clinical outcomes, greater patient reliance on direct healthcare structures, and associated increases in healthcare costs. As such, further research on the prevalence, nature, and impact of impaired mastication is warranted to inform the need to design interventions for TMD-related eating and swallowing problems.

Masticatory Pain

Pain impacts on the assumption and maintenance of personal, occupational, and societal roles, with the potential for secondary emotional distress, degradation of self-efficacy, self-construct, and emotional well-being if not managed appropriately(130–136). Unmanaged chronic pain is estimated to cost the North American economy between $261 and $300 billion per annum, exceeding the total costs associated with heart disease, cancer, and diabetes(137). Orofacial pain is a determining factor in treatment-seeking by adults with TMDs, and masticatory pain impacts on both functioning and well-being(138), with previously pleasurable activities such as eating becoming associated with negative outcomes. It is hypothesised here that chewing pain may cause adults with TMDs to break down solid boluses less, resulting in them swallowing larger, potentially unsafe, amounts. In addition, it is hypothesized that pain may be associated with the use of modified diets as pureed foods may require less pain-provoking TMJ movements to chew, although supporting evidence on this topic is currently limited.

Research suggests that masticatory pain is experienced by most adults with TMDs (see Table 3), although identified methodological and theoretical limitations exist(127,139–143). For example: the provision of limited detail on participant demographics or methods of statistical analysis, and recruitment of participants presenting with unspecified and/or mixed symptom profiles, thus reducing the external validity of findings(140).

Table 3: Studies reporting on the Prevalence of Masticatory Pain

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Michelotti et al.,(139)	2002	University clinic	RCT	63	Unclear	Unclear	100%
La Touche et al.,(140)	2015	Specialised private practice facial pain clinic and public health centre	Case-control	33	Unclear	Unclear	96.38%
Dougall et al.,(143)	2012	General dental practice	Descriptive observational	185	4.28:1	42.68 (unclear)	89.72%
Gavish et al.,(141)	2000	University clinic	Prospective cohort	49	2.76:1	29.2 (+-7.8)	83.67%
Da Silva et al.,(127)	2011	University clinic	Case-control	70	0.84:1	53 (unclear)	72.2%
Reißmann et al., (116)	2007	University clinic	Case-control	312	3.16:1	38.6 (+-15.6)	68.53%

Although several studies have reported lower prevalence estimates(116,127), discrepancies may relate to the use of subjective assessments alone, as studies reporting higher estimates also incorporated chewing tasks. As such, the use of functional assessments may increase the accuracy of future epidemiological findings. In addition to these limitations, although research on the presence of masticatory pain exists, minimal investigation of its potential impact on overall bolus formation, eating, swallowing, or nutrition has been conducted. Therefore, future research is required to determine the nature of this pain, its potential contribution to impairments in eating and swallowing, and the most effective treatments for this issue.

Masticatory Fatigue

Fatigue is defined as subjective physical and/or cognitive tiredness, loss of energy, and lack of initiating or maintaining voluntary effort, with subsequent impact on the actualisation and maintenance of personal, social, and occupational roles, and HRQOL(144–147). Research suggests that oral stage masticatory fatigue is commonly reported by adults with TMDs due to impairments in muscular contractions (see Table 4).

Table 4: Studies reporting on the Prevalence of Masticatory Fatigue

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
La Touche et al.,(140)	2015	Specialised private practice facial pain clinic and public health centre	Case-control	33	Unclear	Unclear	98.79%
Ferreira et al.,(125)	2017	Specialised private practice facial pain clinic and university hospital clinic	Case-control	12	12:0	37 (+-16)	66.6%
Foteder et al.,(123)	2015	University hospital clinic	Cross-sectional	195	5.91:1	34.8 (+- 17.2)	50.61%
Reißmann et al., (116)	2007	University clinic	Case-control	312	3.16:1	38.6 (+-15.6)	45.91%
Barros et al.,(119)	2008	University clinic	Cross-sectional	132	4.92:1	36.5 (+-13.5)	33.73%

Yet, few studies have been completed on this topic, and methodological critique includes the frequent use of subjective assessments, with no IROM indices of muscle endurance, physiological fatigue, or functioning collected(140). In addition, while estimates suggest that up to 99% of adults with TMDs may experience masticatory fatigue, limited research on the subsequent impact of this fatigue has been conducted. It is hypothesised that masticatory fatigue associated with TMDs may result in reduced masticatory effectiveness, lengthened mealtimes, avoidance of eating, reduced oral intake with systemic consequences, and secondary anxiety and/or embarrassment. Therefore, patients with masticatory fatigue may require greater clinical and research attention in order to ensure that these potential consequences are understood and managed, as appropriate.

Impaired Swallowing

As discussed, difficulties at the oral phase of swallowing in adults with TMDs are documented (e.g.: masticatory impairments). However, these difficulties may result in individuals with TMDs

swallowing large un-masticated boluses, potentially causing secondary uncomfortable, yet protective, reactive responses (e.g.: gagging or choking), with associated tertiary emotional ramifications (e.g.: fear, embarrassment, or anxiety). As outlined, minimal research has addressed impaired deglutition within this group. Therefore, limited data is available on the prevalence, nature, or impact of this issue. Studies which have investigated impaired swallowing in adults with TMDs report varied findings (see Table 5).

Table 5: Studies reporting on the Prevalence of Impaired Deglutition

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Maffei et al.,(114)	2012	Unclear	Descriptive observational	10	1.5:1	Unclear	70%
Da Silva et al.,(127)	2011	University clinic	Case-control	70	0.84:1	53 (unclear)	16.6%
Raphael & Marbach(124)	2001	University clinic and general dental practice	RCT	63	1:0	33.7(+-10.9)	7.93%
Baker et al.,(126)	2015	University clinic	RCT	34	10.3:1	38.9 (+- 15)	5.88%
Mapelli et al.,(118)	2016	University clinic	Case-control	30	9:1	30.5 (unclear)	0%
Ferreira et al.,(125)	2017	Specialised private practice facial pain clinic and university hospital clinic	Case-control	12	12:0	37(+-16)	0%
De Felicio et al.,(129)	2012a	University clinic	Case-control	30	1:0	30(+-8)	0%

Despite studies such as Maffei(114) reporting a high prevalence and varied nature of swallowing difficulties secondary to impaired oral stage functioning, results are equivocal, with several studies reporting that impaired swallowing is not experienced by this group(60,118,129). These studies have used the Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD) examination protocol(148) and the ProTMDmulti Protocol Part-II(149), both of which make only brief references to swallowing. In addition, the majority of these studies have also used masticatory muscle electromyography (EMG) or surface EMG (sEMG), without attention to oral or oropharyngeal bolus transit. Furthermore, a wide spectrum of professionals with different clinical backgrounds have been involved in data collection (e.g.: physicians, dentists, and oral and maxillofacial surgeons (OMFS))(124,150,151). However, few studies have included the speech and language therapist (SLT) who is the professional most frequently involved in the clinical management of eating and swallowing difficulties in other patient groups(114). Finally, theoretical issues include the provision of heterogeneous academic definitions for swallowing difficulties in this patient group (Claudia Ferreira, Personal Communication, November 2016), with many studies not specifying their operational definition of “impaired deglutition”. As such, understanding of the prevalence, nature, or impact of impaired swallowing in adults with TMDs is limited.

Unintentional Weight Changes

TMDs cause jaw pain and dysfunction, resulting in reduced ROM and impaired mastication. Consequentially, individuals with TMDs may reduce their oral intake or alter their typical diets to softer foods which are easier to consume. However, these diets may not be nutritionally optimal, resulting in the consumption of calorie-deficient or imbalanced diets, and unintentional weight

changes. Although no research has been conducted yet to explore this hypothesis, anecdotal patient reports are available on online message forums and blogs. A common theme of these narratives is incremental increases in eating high fat, salt, and sugar (HFSS) items due to chronic masticatory impairments:

> "*I found myself eating more after dinner. One night I would have 2 cups of pudding. The next night I would add on ice cream. In other words, the dessert tray would pile up because I was bored with the white and brown mush."*(152).

In addition, emotional distress due to unintentional weight gain has also been emphasised:

> "*As for the weight gain… I've had to get rid of a lot of clothing lately because I couldn't even squeeze in to it anymore*."(153) .

Research suggests that the eating patterns of most adults in Ireland are incongruent with optimal health, with typical consumption of 3 times the recommended weekly amounts of HFSS food items(154). Most of the adult Irish population are overweight or obese, with resultant effects on systemic and psychological health and work productivity(154). Therefore, individuals with TMDs may habitually consume imbalanced pre-morbid diets, with further modifications to accommodate masticatory issues. As such, they may be at a higher risk for developing secondary systemic consequences than those without TMDs.

In contrast to weight gain, it is suggested that individuals with TMDs may also reduce, alter, or cease all oral intake due to masticatory impairments, resulting in unintentional weight loss. Reports suggest that individuals with non-refractory masticatory impairments may adopt a liquidised diet or remain nil per os to avoid exacerbation of discomfort, with subsequent weight loss:

> "*it is SO painful all the time and i have lost so much weight because i can't chew"*(155).

A common theme is distress associated with hunger, with subsequent effects on systemic health, functioning, and emotional well-being:

> "*I lost 20 lbs in 6 weeks. At one point I was horribly nauseous all the time because my body didn't know how to process the level of hunger I was feeling.*" (156);

> "*Ultimately [TMD] sucks though because I'm literally SO hungry. We've been juicing up a storm & incorporating a lot of smoothies & vitamins in to my daily regime but I'm still always hungry. I can't stop losing weight, which sounds fun for a week, but it's not*"(157);

> "*I'm hopeful that this flare won't last as long as the last one. After all, I'm doing the liquid diet thing solely to get my jaw back to a place where I can chew or talk or smile without pain, not because I'm looking to lose a quick five pounds… The issue is that, well, I'm hungry. A lot.*"(158).

This distress may be further perpetuated by the fear of ongoing weight loss due to chronic masticatory, eating, and swallowing difficulties and associated increases in functional and emotional discomfort:

> "*I'm concerned about this. I have TMJ joint surgery scheduled… I've already lost 40lbs in 7 months from having difficulties eating from the TMJ. Im* [sic] *worried after surgery im* [sic] *going to lose even more weight*".(159);

> "*It has come to the point I can't even look* [at] *food ☹ when I look at it and all I see it P A I N! … I have been drinking smoothies I make at home and apple sauce and jello, am I going to get sick if I keep eating like this?*"(160) .

These narrative accounts emphasise that unintentional weight loss is a patient-prioritised issue, thus warranting greater research to inform future care delivery. In light of these hypothesised negative outcomes, individuals with TMDs may require additional clinical monitoring of oral intake, nutritional and body mass index (BMI) status, and overall systemic and psychosocial well-being(161). Therefore, future research is required to deepen our understanding of the epidemiology, nature, and impact of this condition, to supplement currently available narrative accounts, and to inform the need for research on its effective management.

1.3.2. The Epidemiology, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders associated with Rheumatoid Arthritis

As noted, individuals with RA may be at greater risk of developing TMDs than those with non-inflammatory conditions(162). Therefore, masticatory impairments may occur at a higher rate in this group due to inflammation-related processes which damage and ultimately destroy the TMJ if left untreated(162). As such, there may be an elevated risk of developing eating and possibly swallowing difficulties in this group, as will now be discussed below.

Impaired Mastication

Although impaired mastication in adults with RA-related TMDs has recently received research attention, prevalence figures are inconsistent (see Table 6). This variation may be due to the use of unspecified or heterogeneous assessment protocols. For example, several studies have used subjective questionnaires alone(151,163), while a range of studies also supplemented these methods with additional dental examinations(150,164). Finally, a series of studies also used hybrid protocols of subjective techniques and IROMs(165–168). These estimates ranged from 25% to 70%, with IROMs including radiography, computed topography, and MRI. However, no studies used dynamic tools (e.g.: videofluoroscopy (VFSS)) and data was not gathered on functional masticatory performance. Therefore, true prevalence estimates may be different to those presented in previous research.

Table 6: Studies reporting on the Prevalence of Impaired Mastication in adults with Rheumatoid Arthritis

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Franks(166)	1969	Rheumatology Hospital	Case-control	100	3:1	Unclear	69%
Ahola et al.,(163)	2015	Database of Finnish Rheumatism Association	Cross-sectional	282	Unclear	Unclear	54.25%
Bessa-Nogueira et al.,(150)	2008	Rheumatology Department, University Hospital	Descriptive observational	61	9:1	Unclear (24-76)	39.3%
Yilmaz et al.,(167)	2012	Rheumatology Department, University Hospital	Case-control	28	13:1	Unclear (35.51-52.49)	37.9%
Aceves-Avila et al.,(169)	2013	Rheumatology Department, University Hospital	Case-control	92	Unclear	Unclear	26%
Bono et al.,(168)	2014	Rheumatology Department, University Hospital	Case-control	95	5:1	45(24-74)	23.24%
Kallenberg et al.,(170)	1997	Rheumatology Department, University Hospital	Case-control	81	10.5:1	56.1(22-80)	19%
Hoyuela et al.,(164)	2015	Rheumatology Department, University Hospital	Cross-sectional	75	Unclear	Unclear	17.3%
Larheim et al.,(165)	1983	Health center	Case-control	49	4:1	58(Unclear)	2.04%

Similar to non-inflammatory conditions, the potential for oral preparatory masticatory impairments to impact on overall deglutition, nutrition, and well-being has been under-explored, with potential subsequent implications for care delivery. Therefore, greater research on this topic is required to inform future care provision to this group.

Masticatory Pain

As discussed, systemic articular pain is a cardinal symptom of RA, with increased pain inversely associated with decreased HRQOL(171). Masticatory pain may develop due to peripheral TMJ manifestations of RA, although prevalence estimates of this issue differ, ranging from 10%(172) to 95%(173) (see Table 7). This heterogeneity creates confusion about the true prevalence and significance of this issue, which may impact negatively on clinician awareness and care provision. Factors potentially contributing to this heterogeneity include: 1) the use of varied assessment protocols; 2) the infrequent use of functional chewing and pain provocation tasks in data collection, and 2) the variable gender ratios within these studies which may impact the representativeness of findings (e.g.: 2:1(163) to 11:1(162)).

However, while remaining cognizant of this heterogeneity, reported masticatory pain rates among RA cohorts are typically higher than those pertaining to other rheumatic disorders or healthy controls. For example: Chalmers and Blair(172) estimated that 10% of patients with RA experience masticatory pain, compared to 2% of mixed osteoarthritis (OA)/healthy controls. Similarly, Helenius et al.,(162) detected masticatory pain in 42% of patients with RA, while patients with mixed connective tissue disease and healthy controls reported lower rates of 31% and 21%, respectively. This was reinforced by Ogus(174) who found that 19% of patients with RA and 4% of healthy controls experienced masticatory pain, and Könönen et al.,(175) who reported

that masticatory pain experienced by 25% of patients with RA was due to joint inflammation and capsule stretching. Yet, although masticatory pain is commonly experienced by patients with RA-related TMDs, consideration of its potential impact on subsequent stages of swallowing and overall eating has been limited. Therefore, as inflammatory joint changes are central to RA disease processes, and remaining cognizant of the symbiotic relationship between unmanaged pain and reduced HRQOL, activity and participation, future investigations of the presence, nature, and impact of masticatory pain are advised to inform the delivery of future evidence-based care.

Table 7: Studies reporting on the Prevalence of Masticatory Pain in adults with Rheumatoid Arthritis

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Voog et al.,(173)	2003	Stomatology Clinic, University Hospital	Descriptive observational	19	8.5:1	Unclear	95%
Ahmed et al.,(176)	2013	Rheumatology Department, University Hospital	Descriptive observational	33	7.25:1	Unclear	74%
El-Assy et al.,(177)	1994	Rheumatology Department, University Hospital	Case-control	30	9:1	Unclear	50%
Helenius et al.,(162)	2005	Rheumatology Department, University Hospital	Case-control	24	11:1	48.9 (37.5-60.3)	42%
Ogus(174)	1975	General hospital	Case-control	62	2.8:1	Unclear (21-79)	36%
Könönen et al.,(175)	1992	Rheumatology Department, University Hospital	Case-control	61	7:1	Unclear (24-80)	25%
Goupille et al.,(178)	1993	Unclear	Case-control	26	5.5:1	62.1(50.3-73.9)	19.23%
Ahola et al.,(163)	2015	Database of Finnish Rheumatism Association	Cross-sectional	282	Unclear	Unclear	12.41%
Chalmers & Blair(172)	1973	Unclear	Case-control	100	3:1	Unclear (18-77)	10%

Masticatory Fatigue

Fatigue originating from RA-related pain, sleep difficulties, and emotional disturbances is experienced by over 80% of individuals with RA(179–181), and has been described as a global, chronic, and pathological tiredness, often perceived to be untreatable and intractable(182,183). Fatigue has been identified as a cardinal distinguishing factor in whether patients with RA are doing subjectively well or poorly(184). However, masticatory fatigue caused by RA of the TMJ has been minimally investigated(151,163,185), and there has been no investigation of its potential contribution to difficulties at subsequent stages of swallowing.

Published prevalence estimates vary from 6% to 55% (see Table 8). Most studies have collected data on masticatory fatigue using subjective assessment methods(151,163,185). However, no identified studies have reported prevalence rates using EMG to measure indices of muscle fatigue and reduced endurance and exercise tolerance, potentially impacting on the reliability and validity of findings and the ability to design targeted, evidence-based, interventions. In addition, the lack of cohesive findings combined with minimal investigation of the potential repercussions of masticatory fatigue on nutrition and deglutition may cause clinicians to underestimate the extent and impact of masticatory fatigue in this group, with implications for care provision. As such, future

research should use a hybrid approach of both subjective and IROMs to explore masticatory fatigue while also investigating the potential consequences of this issue for overall eating and swallowing.

Table 8: Studies reporting on the Prevalence of Masticatory Fatigue in adults with Rheumatoid Arthritis

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Tegelberg(185)	1987	Rheumatology Hospital	Case-control	151	4:1	Unclear (21-82)	55%
Kallenberg et al.,(170)	1997	Rheumatology Department, University Hospital	Case-control	81	10.5:1	56.1(22-80)	19%
Ahola et al.,(163)	2015	Database of Finnish Rheumatism Association	Cross-sectional	282	Unclear	Unclear	6.02%

Impaired Deglutition

Research suggests that adults with RA may be at risk of developing oropharyngeal dysphagia due to the pathological effects of this disease on the cricoarytenoid joints(99), with resultant impairments in airway protection. However, few studies have specifically investigated if impaired mastication caused by RA-related TMDs has repercussions on the overall swallowing process. Studies which have been completed demonstrate heterogeneity in methodological design, participants recruited, and sources of assessment data(150,151,186). Perhaps as a consequence of this variability, differing estimates of impaired deglutition have been reported (see Table 9).

Table 9: Studies reporting on the Prevalence of Impaired Deglutition in adults with Rheumatoid Arthritis

Study	Date	Setting	Study design	No. of TMD patients studied	Gender ratio (F:M)	Mean age (SD) (years)	Prevalence
Ekberg et al.,(186)	1987	Radiology and Internal Medicine Department, University Hospital	Descriptive observational	31	4.1:1	Unclear	33.3%
Kallenberg et al.,(170)	1997	Rheumatology Department, University Hospital	Case-control	81	10.5:1	56.1(22-80)	30.86%
Bessa-Nogueira et al.,(150)	2008	Rheumatology Department, University Hospital	Descriptive observational	61	9:1	Unclear (24-76)	13.10%

Studies using subjective measures alone(150,151) have reported lower estimates than those using reference standard IROMs for the investigation of deglutition (e.g.: VFSS) (186), suggesting that future research using hybrid protocols is required to detect true prevalence rates and to inform future management. In addition, as greater levels of research have been conducted on the effects of RA on airway protection, awareness of the potential for RA-related TMDs to impact on deglutition is minimal, thus potentially masking the true functional status and clinical needs of this group. Therefore future investigations in this field are warranted.

Unintentional Weight Changes

A range of factors may contribute to unintentional weight changes in adults with RA. To begin, the disease processes involved in RA pathogenesis may themselves result in weight loss,

malnutrition, rheumatoid cachexia, and obesity(187,188). In addition, it is hypothesised that cellular and morphological TMJ damage caused by RA may result in masticatory impairments, causing the individual to eat softer foods which may be deficient in essential vitamins, minerals, nutrients, and calories, therefore causing unintentional weight changes, with potential functional, emotional, and systemic implications. However, while research has been conducted on the role of systemic pathological processes in weight changes, no investigations have been completed regarding TMJ-specific factors. Therefore, in the absence of available research evidence, patient reports from online message boards and forums can supplement our understanding.

Systemic weight loss leading to malnutrition is present in up to 71% of adults with RA, with reduced amounts of fat-free mass found even in individuals with low RA disease activity(189). Low BMI is a predictor of worse clinical outcomes, with negative implications on levels of muscle mass and joint destruction(188). As such, malnutrition and weight loss may be contributing factors to increased morbidity and mortality in adults with RA, with some research hypothesising links between increased malnutrition and the presence of RA-related TMDs(190,191). When weight loss caused by RA-related TMDs is reported directly, individuals highlight masticatory difficulties as a causative factor:

> *"I have lost weight … I am managing soft foods, hot chocolate for comfort!!"*(192).

Individuals have emphasised their low baseline weight, and highlight the potential for the development of malnutrition:

> *"Very painful - couldn't chew or swallow for 2 days… Told my dentist... He said it must have been a good way to lose weight! … I don't* [need to]*!"*(193)

focusing on the distress caused by the inability to eat:

> *"It's a horrible pain and I found even eating ice cream painful as we use our jaw muscles to swallow*"(194).

In addition to weight loss and malnutrition, metabolic perturbations can also result in rheumatoid cachexia, or reduced systemic muscle mass in the presence of stable or increased body fat(195–197) in up to 67% of adults with RA(198,199). Cachexia is associated with uncontrolled RA disease processes, and negative systemic, functional, and psychosocial consequences(198). Yet, this is difficult to detect as increased or stable body fat levels and RA-related systemic inflammation mask muscle wastage, resulting in stable BMIs(195,200). Cachexia may be suggested in patient reports of declining all oral intake yet experiencing no weight loss:

> "*Even though I'd found it hard to eat for 3 days I still hadn't lost weight; you'd think there would be some benefits!!!!!*"(201).

Therefore, in light of hypothesised links between cachexia and RA-related TMDs, future investigations are warranted to inform patient-centred care provision.

Furthermore, increased levels of visceral fat, central obesity, and waist circumference are also frequently documented in adults with RA(202,203), with greater than 60% of these patients having elevated BMIs(199), and up to 57% presenting as overweight or clinically obese(199,204,205). There are established links between higher levels of body fat in adults with RA and coronary disease, type 2 diabetes inflammation, insulin resistance, medication resistance, and endothelial dysfunction(189,199,202,206). It is documented that obesity in adults with RA leads to decreased HRQOL, functional capacity, and increased pain and inflammatory activity(199,204,206–208), while individuals with RA who are obese have a 40% lower chance of achieving remission status, and a 50% lower chance of sustaining this status, as compared to those who are not obese(209). Also, at a societal level, obesity associated with RA incurs larger medical costs, longer hospital stays, and decreased workforce productivity(204). In addition to these systemic effects, there is also the potential for individuals with RA-related TMDs to gain weight unintentionally, secondary to eating soft, pre-processed convenience foods due to impaired mastication, for example:

> *"Eat soft foods. Good excuse for ice cream."*(210).

However, this topic has received minimal research attention, with possible implications for service delivery. Therefore, research into the potential consequences of masticatory impairments on overall eating and nutrition is required to inform future care provision to this patient group.

1.4. Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Typical Clinical Management

Clinicians working in the field of chronic orofacial pain frequently report that they feel ill-equipped to manage TMD signs and symptoms and often describe clinical involvement with these patients as unrewarding, protracted, and challenging, with difficulties achieving meaningful clinical outcomes(211–213). The lack of clinical protocols, resources, or education to guide management are typically cited as contributing factors to this dissatisfaction (211–213). Therefore, as there is limited research to guide clinicians in their management of even the most established TMD signs and symptoms (e.g.: impaired mastication), it is hypothesised that minimal awareness, assessment, or treatment of potential secondary difficulties in eating or swallowing currently exists. The typical clinical management of TMDs will be discussed in subsequent sections.

1.4.1. The Assessment of Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Typical Procedures and Problems

The historical assessment of TMDs is controversial(163,170,185). For much of the 20th century, assessment involved description of the physical structure, position, and function of the articular disc and occlusal support of the mandible alone, although this approach lacked evidence-based support(214). Subsequently, TMD assessment was influenced by the psycho-analytical viewpoint(215) which hypothesised that chronic pain conditions were external psychosomatic manifestations of underlying anxiety neuroses. Therefore, individuals with TMDs who did not

benefit from treatments addressing disc position or occlusal contacts were often diagnosed with conversion disorders and referred for psychiatric evaluation, leading to negative stigma and unsatisfactory clinical outcomes. These assessment practices were only challenged with the emergence of the biopsychosocial model of illness and disease, which values clinical, IROM, and subjective findings, with consideration of the true impact of illness on the functioning and well-being of the patient(214,216).

As discussed, specific research on the potential for impaired mastication to cause secondary problems in eating and swallowing among adults with TMDs is limited. In addition, it is hypothesised that as these patients may not experience laryngotracheal penetration or aspiration pneumonia, they therefore do not regularly present for acute medical care, thus further reducing the perceived significance of these potential eating and swallowing issues or the clinical urgency to assess for their presence. When patients with TMDs do seek treatment, they most frequently present to their general dental practitioner (GDP)(15,32,176). GDPs are experienced in the management of acute orofacial pain caused by issues such as dental caries, which are frequently remediated by direct impairment-based intervention (e.g.: extractions), without implications for other bodily functions or systems. As such, these clinicians may not frequently encounter secondary eating or swallowing problems in typical practice, resulting in reduced awareness of the need to assess for these symptoms.

When assessment does take place, researchers and clinicians must rely on non-cohort specific subjective assessment protocols, which may not be suited for use with this patient group and which may inadequately profile such difficulties (see Figure 7) (15,148,217–220,220–225). These tools focus on disparate aspects of TMD aetiology and nature, and they infrequently address potential eating or swallowing concerns. In addition, although orthopantomogram and lateral cephalometric radiographs are commonly used in research and clinical practice to view the static dental, articular, and osseous components of the TMJ complex, these methods provide limited information on impaired mastication or potential eating and swallowing difficulties due to their lack of focus on functional movements. Furthermore, dynamic and functional assessments of swallowing such as VFSS or the Test of Masticating and Swallowing Solids (TOMASS))(226) have been minimally used in TMD research to date, potentially due to the lack of SLTs involved in these investigations thus far(114,186). Although this may perpetuate clinicians' lack of awareness of these tools and their potential role with this patient group, critical examination of the role and function of currently existing tools suggests that they may be limited in their ability to accurately and objectively capture the complex effect of impaired mastication, pain, and fatigue on overall deglutition due to their focus on airway protection and IROMs, respectively. Therefore, it is evident that due to a confluence of a factors, public, clinical, and academic awareness of the potential for eating and swallowing difficulties in adults with TMDs is limited, which, combined with a lack of available and appropriate tools, acts as a barrier to their assessment. As such, further research is required to investigate the potential for the development of these difficulties in this

group, and to subsequently advocate for and inform the design of cohort-specific assessment tools for use with patients with TMDs who experience eating and swallowing problems.

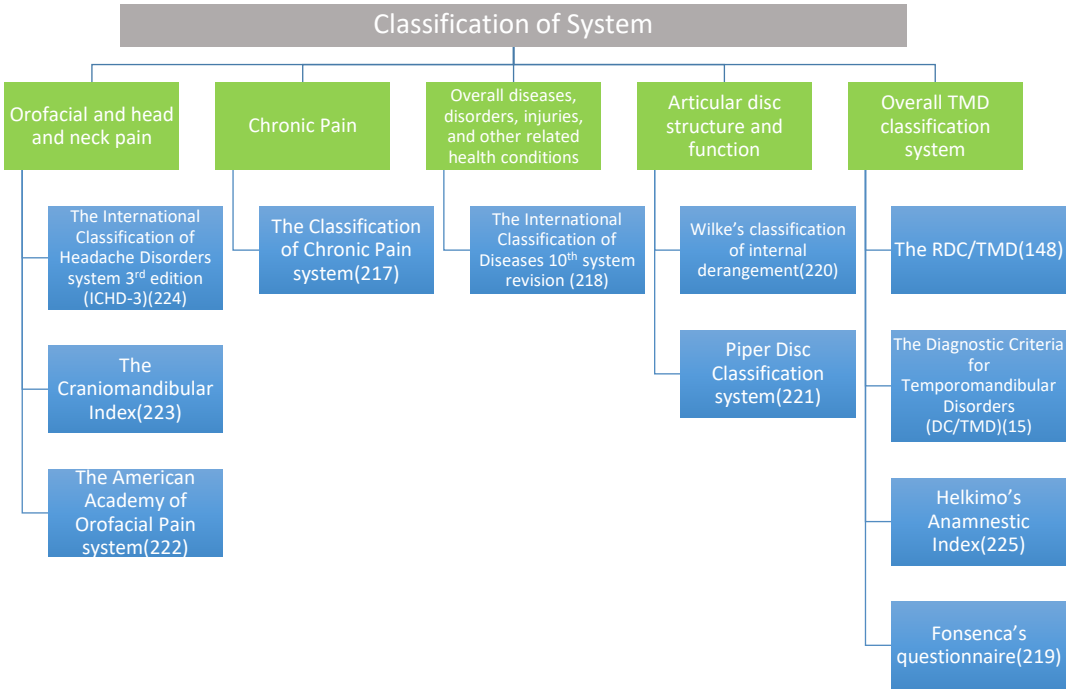


Figure 7: Evaluation and Classification Systems used in TMD Research and Practice

1.4.2. Intervention for Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Current Status and Challenges

Research suggests that TMDs develop due to the atypical interaction of structural, functional, pathophysiological, and socioemotional factors which disrupt the balance of the masticatory system (see Section 1.2.1.). As such, in order to provide effective intervention for TMDs, clinicians must address both isolated contributing factors, and indeed, the interaction between these factors. In light of the many potential contributing factors, a spectrum of interventions are available for the treatment of TMD signs and symptoms(227,228) (see Figure 8). However, the most recent meta-analysis on the effectiveness of these interventions is almost 10 years old, with the potential that more modern therapies or evidence have emerged since publication(228). Therefore, updated research of commonly used interventions is required.

Due to the factors discussed previously, awareness and assessment of masticatory impairments and the potential for these to cause subsequent difficulties in the overall eating process are limited (see Section 1.4.1.). Therefore, it is hypothesised that the clinical rehabilitation of these issues is also uncommon. Few available TMD interventions directly address impaired mastication, resulting in reduced potential for the rehabilitation of both this primary difficulty and any potential associated secondary consequences (e.g.: eating and swallowing problems). The lack of appropriate interventions may contribute to the poor clinical outcomes frequently experienced by this patient

group, as all factors potentially contributing to the development of TMDs may not be currently addressed.

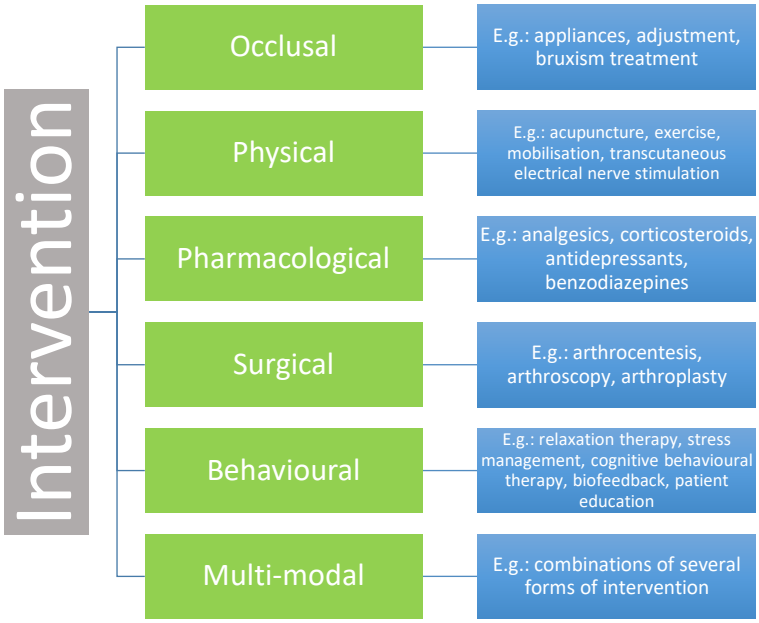


Figure 8: Most Common TMD Treatment Modalities

In response to poor clinical outcomes, it is hypothesised that patients with TMDs may experience symptom chronicity and frustration. This may motivate them to seek further treatments for masticatory difficulties and associated eating and swallowing problems, beyond those typically provided by their GDP (e.g.: alternative, complementary, or energy healing therapies)(229). Online searches retrieve grey literature promoting unscientific “cures” for chronic TMDs, which have no supporting evidence for their efficacy, effectiveness, or safety(230). Engaging with these non-evidence-based treatments potentially risks the physical and emotional well-being of the patient, while also introducing potential financial implications(230–234). As such, it is advised that these difficulties are further investigated to inform the need for future evidence-based treatments which target all contributing factors in TMD development and chronicity, with the view to improve clinical outcomes and cost-effectiveness of service delivery(228).

1.4.3. Overall Management of Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Practical Considerations and Potential Barriers

Mono-disciplinary care is the most frequently employed care model in TMD management. In this paradigm, a single clinician assumes responsibility for the management of all TMD-related signs and symptoms. This clinician is most frequently the GDP for patients with non-inflammatory conditions and the rheumatologist for those with RA(15,32,176). The GDP often operates within a system which promotes financial competition between colleagues, leading to isolation, limited communication, and dissatisfaction with care provision(235). Potentially due to this isolation, GDPs often report insecurity about staying abreast of contemporaneous research on the accurate diagnosis, selection of evidence-based treatments, and appropriate determination of clinical

outcomes in patients with TMDs(236,237). Therefore, it is essential that greater guidance is provided for clinicians, and that multi-disciplinary team (MDT) collaboration is promoted in order to support them in their provision of care to these patients.

Although MDT management of TMDs is still infrequent, this care model is gradually increasing in clinical popularity(238,239). As discussed, all contributing factors to TMD development and their interactions must be addressed in order to provide effective intervention(238). As such, the collaboration of a range of healthcare professionals to assess, diagnose, design, and deliver a shared management plan based on these factors may enhance clinical outcomes and patient recovery(238,240,241). Recent reports have been published on the establishment of MDT care structures for TMD management(176,239,242). These clinics are typically led by consultant OMFS with specialist interests in TMDs, with close collaboration between a range of other medical, surgical, dental, and allied health professionals(242). Typically, patients are independently assessed by each professional, with findings shared, and subsequent collaborative initiation of MDT intervention(242). Thus far, clinical outcomes from these clinics have documented decreased pain intensity, improved mandibular functioning, improved satisfaction with care, and enhanced HRQOL(176,239,242). However, studies on this topic have been methodologically criticised(243), and therefore, future robust research on the impact of MDT care on both generalised TMD issues and specific eating and swallowing difficulties is warranted.

Finally, although discussions of MDT involvement in TMD care typically reference the collaboration of professionals such as OMFS, GDPs, medical physicians, surgeons, neurologists, rheumatologists, anaesthetists, pharmacists, physical therapists, and psychologists(239,244), no references have been made to the inclusion of the SLT or dietitian, despite the documented prevalence and hypothesised repercussions of impaired mastication on eating and swallowing(176,239). Therefore, future research is warranted to investigate the potential contribution of these specialists to the effectiveness and feasibility of TMD management.

1.5. Summary and Conclusions

In Chapter 1, available literature on masticatory impairments in adults with TMDs and the hypothesised subsequent eating and swallowing difficulties which these patients may experience was reviewed. Rationale was also provided for the need to conduct further research on the epidemiology, nature, impact, and management of these issues, with the view to add to the professional knowledge base and to ultimately inform the provision of clinical care to this patient group. Overall, this dissertation is presented in 4 sections: 1) an introductory review of available literature and the theoretical framework; 2) discussion of the research conducted and results generated on eating and swallowing difficulties in patients with non-inflammatory TMDs; 3) specific exploration of investigations conducted and findings generated on patients with inflammatory-based TMDs; and 4) discussion of overall results, research implications, and conclusions. The specific structure of the following chapters is as follows:

- Chapter 2 presents the theoretical framework which acts as the foundation of this research, while also discussing the research aims and questions;
- Chapters 3 to 10 describe the methods used to conduct a series of interlinked research studies, with brief discussion of the results generated;
- Chapter 11 broadly discusses the findings of this research and examines both limitations and clinical and research recommendations.

Chapter Two: The Theoretical Framework of Research

2.0. Introduction

In this chapter, the theoretical framework supporting the investigation of the epidemiology, nature, impact, and management of eating and swallowing problems in adults with TMDs will be discussed, in conjunction with presentation of the research aims and questions.

2.1. The Theoretical Framework of this Research

As noted in Section 1.2., TMDs are prevalent among the general population, with research suggesting that up to 9 out of every 10 adults experience TMD symptoms at some point during their lifespan(27,32,34), with this dysfunction caused by either non-inflammatory or inflammatory conditions. Within this cohort, most individuals with TMDs report oral preparatory masticatory impairments(115) (see Section 1.3.). Furthermore, the majority of these individuals report that pain and fatigue also impact on mastication (up to 100% and 99%, respectively)(139,140). Despite this high rate of difficulties at the oral preparatory stage of swallowing, there is minimal awareness regarding the potential consequences of these issues on the overall eating and swallowing process. The theoretical framework for this study is that adults with oral preparatory impairments may subsequently experience eating and possibly swallowing difficulties, as they attempt to swallow large un-masticated solid boluses. This may result in primary motoric difficulties (e.g.: impaired oropharyngeal transit due to large bolus size), associated with secondary protective responses (e.g.: gagging or choking), and tertiary emotional ramifications (e.g.: anxiety about the potential for choking). These experiences may lead to the individual modifying their typical oral intake to accommodate masticatory impairments and avoid these experiences. It is also hypothesised that patients with inflammatory conditions (e.g.: RA) may experience more severe difficulties in eating and swallowing than those with non-inflammatory symptoms (e.g.: MFP) due to the impact of inflammatory joint destruction on TMJ functioning.

However, limited research has been conducted on the prevalence, nature, or impact of these potential eating and swallowing problems on physical functioning or emotional well-being. This is hypothesised to be due to the interaction of several factors. For example: as these difficulties are hypothesised to originate at the oral preparatory and oral stage of swallowing, airway protection may not be impaired, and therefore patients may not present for emergency medical care, thus reducing clinicians' awareness of these difficulties. In addition, when patients with non-inflammatory TMDs do present for treatment, it is most frequently to their GDPs, with some presenting to other clinicians with dental training (e.g.: oral surgeons, prosthodontists, OMFS). Patients with RA-related TMDs most frequently present to rheumatologists. Due to the lack of research on the potential for eating and swallowing problems to develop in this group, and a subsequent shortage of resources or guidelines to adequately support these clinicians to identify or address these difficulties, it is suggested that their awareness and management of these

difficulties is currently limited, with the only available compensatory strategy for use with this group being diet modifications.

Yet, despite this lack of available research and limited current clinical management (see Sections 1.3. and 1.4.), patient narrative accounts are available (see Section 1.3.) which support the need to investigate the prevalence, nature, impact, and management of these problems further. In addition to the narrative accounts, this research is also motivated by the Researcher's own personal experience of TMD, which was caused by bilateral DDWOR and subluxation. This was not easily ameliorated by dental, medical, complimentary, or surgical treatments, initially resulting in masticatory issues, with the subsequent development of eating and swallowing problems. Therefore, the theoretical framework of this research is that if oral preparatory issues caused by inflammatory or non-inflammatory TMDs are not appropriately managed from the outset of treatment, they have the potential to impact on overall eating and swallowing, which may affect the patient's physical, emotional, social, and psychological well-being, by reducing their ability to consume typical oral diets, participate in social occasions and ADLs, and maintain occupational and recreational roles.

2.2. Research Aims

The primary aim of this research is to examine the epidemiology, nature, impact, and management of eating and swallowing problems in adult patients presenting with TMDs. A secondary aim of this research is to conduct comparative research specifically investigating these issues in patients with both non-inflammatory (e.g.: MFP or DDs) and inflammatory-related TMDs (e.g.: RA), to supplement the professional knowledge base, and to potentially inform the development of specific intervention techniques which address subgroup differences (see Sections 4.1. and 8.1.). By examining the epidemiology, nature, and impact of these issues, it is intended that clinician awareness will be positively impacted and that future research on eating and swallowing problems in adults with TMDs will be informed by the findings here (see Sections 5.1. and 6.1.). In addition, by investigating the current management of these issues, and the use of diet modifications as a compensatory strategy, it is intended that avenues for improvements in service delivery will be explored, with particular emphasis on promoting accurate assessment of eating and swallowing problems in adults with TMDs, and providing evidence to inform the need to develop cohort-specific interventions for use with this group (see Sections 3.1., 5.1., 9.1., and 10.1.).

2.3. Research Questions

The questions which this research will answer are:

1. What is the epidemiology of eating and swallowing problems in adult patients presenting with non-inflammatory and inflammatory TMDs?

2. What is the nature and impact of eating and swallowing problems in adult patients presenting with non-inflammatory and inflammatory TMDs?
3. How are eating and swallowing problems as experienced by adult patients with non-inflammatory and inflammatory TMDs typically managed by the clinicians to whom they most frequently present for treatment (i.e.: professionals with dental training and rheumatologists)?
4. What is the prevalence of diet modification use by adult patients with non-inflammatory and inflammatory TMDs?

As these are exploratory questions, hypotheses were not proposed before conducting the research.

2.4. Conclusion

This chapter outlined the theoretical framework which will act as the foundation for the investigation of the epidemiology, nature, impact, and management of eating and swallowing difficulties in adults with non-inflammatory and inflammatory TMDs. Research aims and questions were also presented. In Sections Two and Three, the methods used to address the research questions and conduct these studies will be presented along with the results generated. These findings will be subsequently discussed in Section Four.

Section Two

Section Two examines the methods used to satisfy research aims and answer questions pertaining to eating and swallowing problems in adults with non-inflammatory TMDs. In addition, results produced from these studies will also be presented.

Chapter Three: Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Irish Dental Professionals' Perspectives on Management

3.0. Introduction

This study investigated the perspectives of oral surgeons, OMFS, oral medicine and pain consultants, and prosthodontists working in the Irish healthcare system with adults presenting with TMDs in order to explore the typical management of eating and swallowing problems in this group.

3.1. Methods

The methods used to conduct this study will now be presented, focusing on the study design, participants, data collection measures, and techniques used to analyse data.

Study Design

A cross-sectional survey design was used to examine the perspectives of clinicians working in Ireland with patients with TMDs regarding: their typical management of eating and swallowing problems in this group, their perceived significance of these problems, and their MDT referral patterns. Ethical approval was granted by the Trinity College Dublin (TCD) School of Linguistic, Speech and Communication Sciences (SLSCS) Research Ethics Committee to conduct this study (see Appendix 1).

Participants

Two groups of participants were eligible for involvement in this study (see Table 10).

Table 10: Eligibility Criteria

Group 1		Group 2	
Eligibility criteria	• Qualified oral surgeons/ GDPs enrolled in specialist oral surgery training schemes • Practicing in any clinical location within the Irish healthcare system (inclusive of The Republic of Ireland and Northern Ireland)	**Eligibility criteria**	• Members of the Irish Dental Association (IDA) and currently/previously involved in the management of adults with TMDs • Practicing in any clinical location within the Irish healthcare system (inclusive of The Republic of Ireland and Northern Ireland)

Participants were eligible for inclusion in Group 1 if they were qualified/currently training to become oral surgeons who were working in the Irish healthcare system with patients with TMDs. In Group 2, participants were eligible for inclusion if they were clinicians with a background in dentistry (e.g.: GDPs, OMFS, orofacial pain consultants, etc) who were members of the IDA and who were currently/had previously been involved in the management of adults with TMDs. No limitations regarding year of qualification, age, or sex were applied to either group.

Sampling and Recruitment Strategies

Different sampling and recruitment strategies were used across the 2 participant groups (see Table 11).

Table 11: Methods of Sampling and Recruiting Participants

Group 1		Group 2	
Sampling method	• Convenience	**Sampling method**	• Purposive
Recruitment method	• Gatekeeper providing study information and paper surveys to potential participants consecutively presenting to conference	**Recruitment method**	• Gatekeeper sending a standardised email to IDA members with study information and a link to online research survey
Recruitment period	• The 1 day inaugural congress of The Irish Association for Oral Surgery (IAOS) (Dublin, November 2016)	**Recruitment period**	• 4 weeks in August 2017

With regards to Group 1, convenience sampling with a consecutive paradigm was used. The IAOS Executive Officer acted as a gatekeeper and allowed access to the study site and participants. All potential participants were provided with a participant information leaflet (PIL) and research survey on their presentation to the IAOS congress (see Appendices 2 and 3, respectively). The IAOS is the representative body for oral surgeons practicing and/or training within the Irish healthcare system. Approximately 60 oral surgeons were registered with this professional body at the time of recruitment(245). Completion of the survey took 5 minutes and participants subsequently returned the survey to a sealed box in the lobby.

Purposive sampling techniques were used with Group 2. The Vice President of the Irish Dental Council acted as gatekeeper in providing access to professionals with a background in dentistry who were currently/had previously worked with patients with TMDs. This additional sampling was conducted in an attempt to recruit a representative sample of the varied clinicians who typically provide care to patients with TMDs (e.g.: GDPs, OMFS, orofacial pain consultants, etc). A standardised email containing a PIL and a link to the research survey was disseminated to professionals who were members of the IDA, with the online survey remaining open to responses for 4 weeks in August 2017 using the SurveyMonkey.com online platform. Individuals were invited to contact the researcher or research supervisor if they had queries regarding the survey.

Materials Used in Data Collection

A new 13-item survey was used in data collection. This tool was developed via review of previous research on the perspectives of professionals working with patients experiencing TMDs or eating and swallowing problems (see Appendix 3). The survey was initially piloted on 9 SLTs in September 2016, with subsequent minor amendments. The final version sought anonymous information on:

1. Perceptions regarding typical assessment procedures: This section contained questions on the evaluation tools typically used by participants, whether they follow a specific protocol when assessing for eating and swallowing problems in adults with TMDs, and if they are satisfied with available assessments for this patient group.

2. Perceptions regarding typical treatment procedures: This section contained questions on interventions typically used in the management of eating and swallowing problems in adults with TMDs, which clinical outcomes participants believe are important in the

treatment of these patients, and if they are satisfied with available treatments for this patient group.

3. Perceptions regarding typical MDT working patterns: Questions in this section sought information on which MDT members respondents typically refer patients with TMD-related eating and swallowing problems to and which MDT members they would like to work with when managing these patients. It also sought information on whether participants are satisfied with overall care typically provided to these patients.

A qualitative open-ended section was also included which investigated perceptions on typical standards of care delivered to patients with TMDs and eating and swallowing problems.

Data Processing and Analysis

Paper-based raw data was manually extracted, while SurveyMonkey.com presented aggregated raw data for extraction. Quantitative data was descriptively analysed using the Microsoft Excel program (Microsoft, Richmond, WY, USA). Qualitative data was manually extracted and transcribed, with line-by-line coding used to identify recurrent units of meaning and to assign a descriptive code to these units based on their attributes. Theoretical coding was then used to identify relationships between codes and to subsequently group them as per descriptive themes.

3.2. Results

The distribution of recruited participants was as follows:

- Group 1: Overall, 27 oral surgeons were recruited, which represented 79.8% of the total sample;
- Group 2: In total, 3 OMFS, 2 oral medicine consultants, 1 orofacial pain specialist, and 1 prosthodontist were recruited, with this group representing 20.2% (n=7) of the overall sample (see Figure 9).

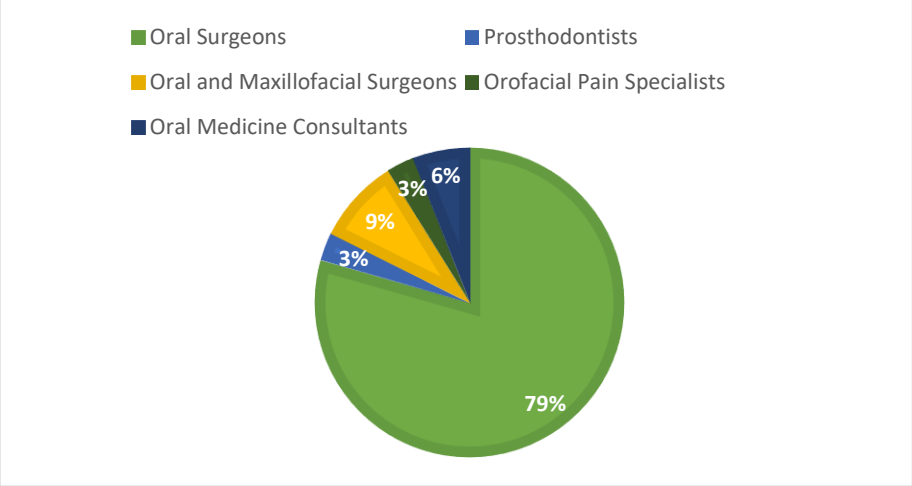


Figure 9: Specialist Training of Participants from both Group 1 and 2

Participant demographics were as follows:

- Group 1: The average number of years of clinical experience reported by these participants was 11-15 years (range: 0- >15 years). Half of respondents (n=15/ 55.6%) had specialised clinical experience in the management of patients with TMD-related eating and swallowing problems. The reported locations of clinical practice were diverse (see Figure 10).

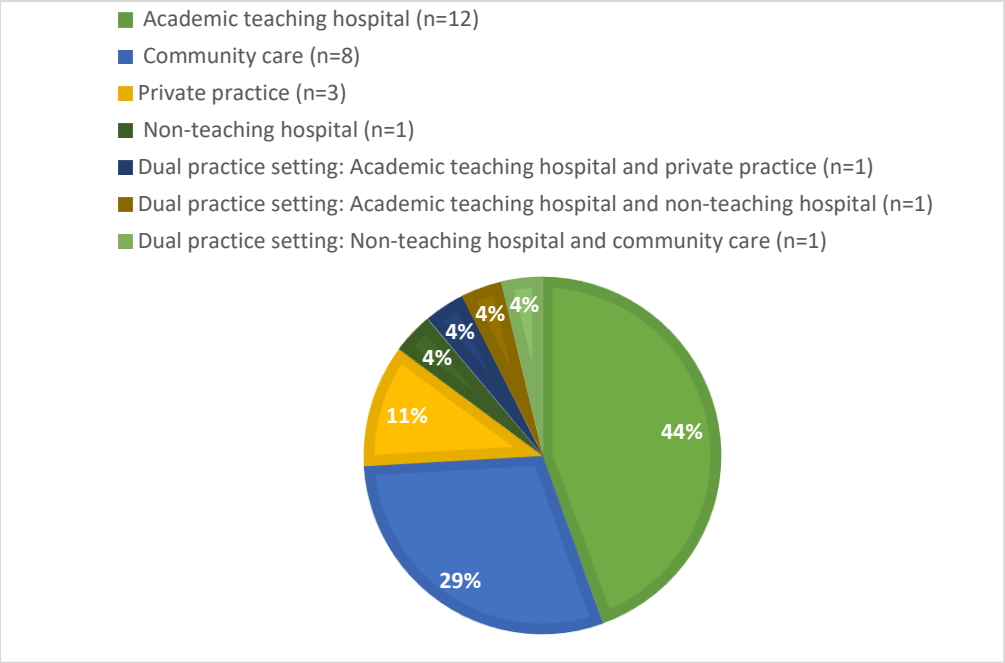


Figure 10: Location of Clinical Practice of Participants in Group 1

- Group 2: Participants also reported on average 11-15 years of clinical experience (range: 0- >15 years). All respondents in this group had specialised clinical experience in the management of patients with TMD-related eating and swallowing problems. Most respondents worked in teaching hospitals (n=6) (see Figure 11).

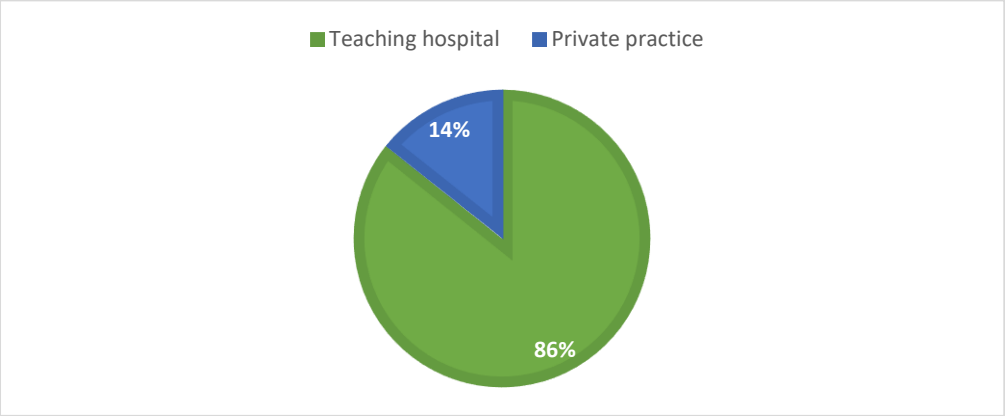


Figure 11: Location of Clinical Practice of Participants in Group 2

The Significance of TMD-related Eating and Swallowing Problems

Participants were asked if they considered eating and swallowing problems in adults with TMDs to be significant issues which warrant specific clinical management. When the overall results from both Group 1 and Group 2 are considered together, almost half of respondents (n=15/ 44%) did not believe that these problems were significant, while 56% (n=19) reported that they were of some significance (see Figure 12).

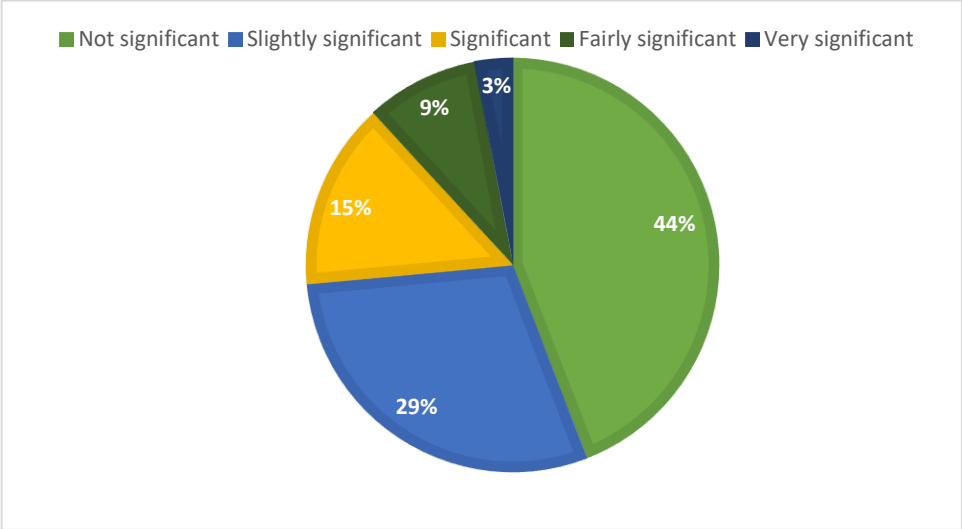


Figure 12: Participants' Consideration of the Significance of TMD-related Eating and Swallowing Problems

Perspectives on Typical Service Delivery: Assessment

Participants were provided with a series of statements on the assessment of eating and swallowing problems in patients with TMDs, and were asked to indicate their level of agreement with these points. Most participants (n=27/ 79.4%) indicated that they do not routinely assess for TMD-related eating and swallowing problems. Participants were also asked about the methods they use when they do assess for these problems (see Figure 13), with subjective examinations (n=13/ 38.23%) and dental assessments (n=11/ 32.35%) being the most commonly used tools.

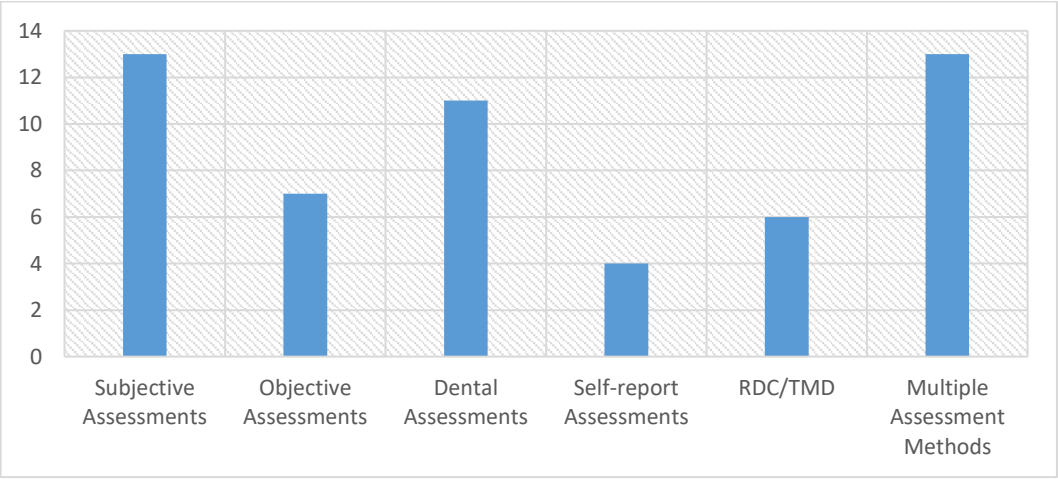


Figure 13: Assessments used by Respondents

Most participants (n=27/ 79.4%) would not alter their typical assessment protocol to investigate eating and swallowing problems in a patient with TMD. Similarly, if a patient experiencing TMD had eating and swallowing problems, 71% of respondents (n=21) would not refer the patient for a VFSS, while 29% (n=10) were unsure if they would make this referral. Attitudes varied on whether participants would refer patients with TMDs to MDT colleagues if they had eating and swallowing problems. While 50% (n=17) agreed that they would, a third (n=12/ 35%) would not complete such a referral. Finally, participants were asked if they were satisfied with available assessments for eating and swallowing problems in adults with TMDs. Half of respondents (n=18/ 53%) reported that they were dissatisfied, while 38% (n=11) were uncertain if they were satisfied. Only 3 participants (9%) were satisfied with available assessment methods. Among the participants with specialised experience with patients experiencing TMD-related eating and swallowing problems, only 3 were satisfied with available assessments (14%), while a third were dissatisfied (n=8/ 36%), and 50% were uncertain (n=11).

Perspectives regarding Typical Service Delivery: Treatment

A third of respondents reported that they typically treat TMD-related eating and swallowing problems (n=11/ 32%). Participants who do treat these problems use a range of strategies (see Figure 14). The most frequently used treatments were: compensatory measures (e.g.: diet modifications) (n=14/ 41%), patient education (n=14/ 41%), occlusal adjustments (n=13/ 38%), and thermal packs (n=12/ 35%). Half of respondents use combinations of treatments (n=17/ 50%).

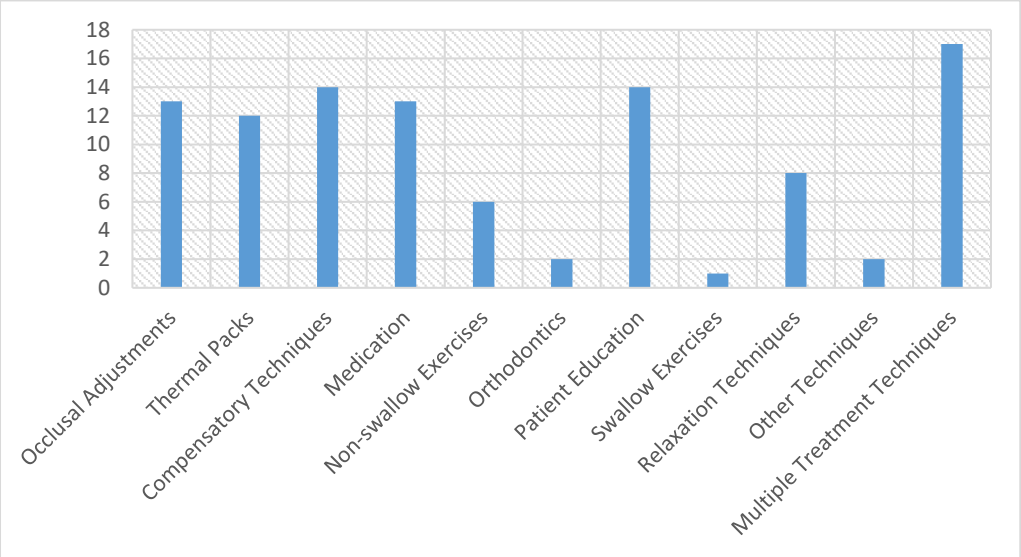


Figure 14: Treatment Methods used by Respondents

The clinical outcomes which participants consider important when treating patients with TMD-related eating and swallowing problems were also investigated. To begin, half of all participants (n=16/ 47%) agreed that improved swallowing was of some significance as a treatment outcome, although 52% (n=18) disagreed or were uncertain. Improved chewing and oral intake were considered important by 85% (n=29) and 74% (n=25) of respondents, respectively. Both improved ROM and reductions in masticatory pain were considered to be of some importance (n=32/ 94%),

while reducing parafunctional behaviour was also considered important by most participants (n=31/ 91%). Most participants considered reduced masticatory fatigue to be an outcome of significant importance (n=29/ 85%). HRQOL improvements were also perceived to be important by 91% (n=31), while patient education was considered important by 97% of participants (n=33). Finally, only 38% (n=13) considered occlusal changes to be important.

In addition to the areas investigated above, respondents were asked if they were satisfied with treatments available for use with this patient group, with half (n=18/ 53%) reporting they were dissatisfied, a third (n=10/ 29%) being uncertain, and only 6 (18%) reporting that they were satisfied with available interventions. Among the professionals with specialised experience in the treatment of these patients, only 27% (n=6) were satisfied with available interventions. Participants provided additional qualitative data on the reasons for dissatisfaction which will be explored in sections below.

Perspectives regarding Typical Service Delivery: MDT Working Patterns

A third of respondents (n=12/ 35%) work in isolation when managing patients with TMD-related eating and swallowing problems. Furthermore, a third (n=12/ 35%) reported that they were satisfied with their current level of MDT input and require no input from additional professionals. When collaboration occurs, the MDT professionals with whom respondents most frequently liaised included: GDPs (n=10/ 45%), SLTs (n=6/ 27%), ear, nose, and throat surgeons (ENTs) (n=6/ 27%), physiotherapists (n=5/ 23%), general surgeons (n=5/ 23%), general medical practitioners (GMPs) (n=5/ 23%), and OMFS (n=5/ 23%) (see Figure 15).

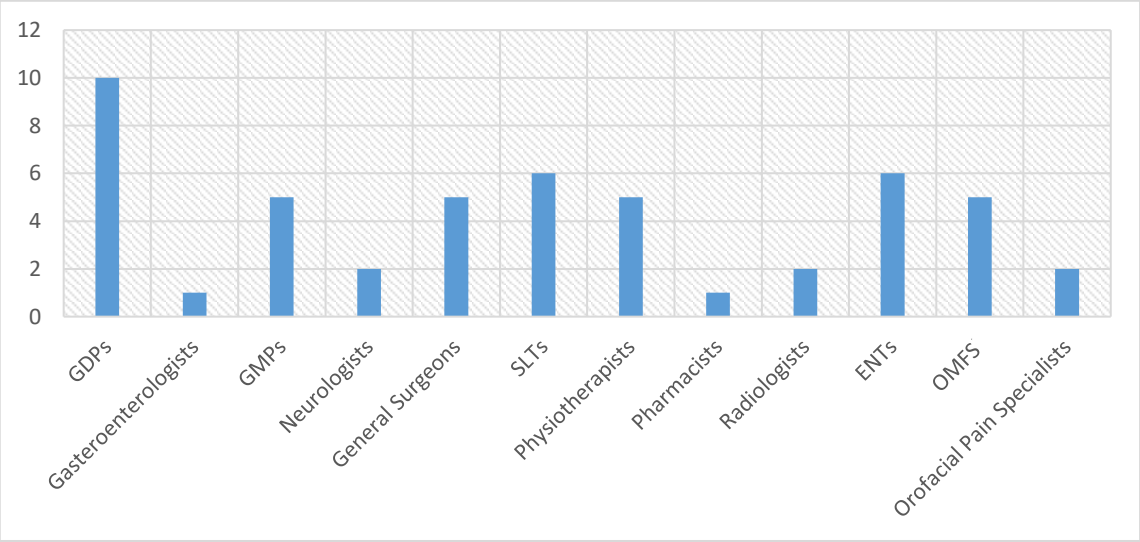


Figure 15: MDT Professionals with whom Respondents Most Frequently Liaise

Respondents were also asked if there were MDT members with whom they would like to liaise when treating patients with TMD-related eating and swallowing problems. For 38% of participants (n=13), SLTs were the professionals with whom they would like to liaise, while a fifth reported that they would also like to liaise with dietitians (n=7/ 21%) or neurologists (n=6/ 18%).

Perspectives regarding Typical Service Delivery: Overall Quality of Care

Participants reported negative views about current standards of care delivered to patients with TMD-related eating and swallowing problems, with half (n=15) reporting dissatisfaction, 35% (n=12) reporting uncertainty, and only 15% (n=5) reporting that they were satisfied. A third of respondents (n=7/ 32%) with specialised clinical experience reported that they were dissatisfied with the overall quality of care provided to these patients.

Four themes emerged during the coding of the qualitative data (see Table 12).

Table 12: Themes of Qualitative Data

Theme	Example
Lack of awareness	Half of participants who completed this section (n=8/47%) highlighted a lack of awareness about the potential for patients with TMDs to develop eating and swallowing problems (e.g.: Participant 1: "*First time I had heard of an association between TMD and [these problems]*"; Participant 4: "*Not enough info* [sic] *on this topic in the GDP field*")
Lack of available research or education	A third of participants (n=6/35%) emphasised the lack of specialised research or training available to support the management of TMD-related eating and swallowing problems (e.g.: Participant 28: *"This is a topic that we know little about even as specialist* [sic]*.";* Participant 6: "*More guidance is required for this specific symptom for pxs* [sic] *with TMD"*)
Lack of satisfaction with typical care provided	A third of respondents who completed this section (n=7/32%) emphasised that they believe that these issues are not managed appropriately in typical practice (e.g.: Participant 32: "*All aspects of TMD including [eating and swallowing problems] not given enough weight*"; Participant 5: "*I feel this area is very poorly managed*"; Participant 30: "*I don't think we consider difficulty with oral stage dysphagia seriously enough*")
Uncertainty in liaisons with the wider MDT	Nine percent of participants who completed this section (n=2) were unsure about which MDT members were the most appropriate with whom to liaise when treating these patients (e.g.: Participant 20: "*Unsure who to refer to in this situation*"; Participant 19: "*Would be nice to get uptodate guidelines*")

4.3. Discussion

This study investigated the views of oral surgeons, OMFS, oral medicine and pain consultants, and prosthodontists working in the Irish healthcare system, with varying levels of experience in managing eating and swallowing difficulties in adults with TMDs, about the clinical significance of these problems, the processes typically involved in their management, and clinicians' satisfaction with current standards of care. As anticipated, the surveyed professionals reported limited involvement in the management of eating and swallowing difficulties in adults with TMDs. It was hypothesised here that due to the complex presentation of these patients and the limited research in this field, that there would be low levels of awareness among participants regarding the potential for patients with TMDs to develop eating and swallowing difficulties. Support for this hypothesis was provided here, with 44% of surveyed clinicians perceiving these problems to be insignificant, and 47% of participants who provided qualitative comments emphasising their own lack of awareness. In addition, a third of participants who provided qualitative comments reported the need for guidance and education on the management of eating and swallowing difficulties in

adults with TMDs. This emphasises the need to conduct future research on the epidemiology, nature, impact, and management of these issues, with the view to inform future care provision.

As noted, it was hypothesised that clinical involvement with this patient group is currently limited. However, it was unanticipated that when clinicians do address eating and swallowing difficulties during TMD management, half of those surveyed here would have overall negative views regarding care provision. It is suggested that despite the small sample size, these findings may be representative of the target group of professionals, as due to the lack of appropriate supports in this field, negatives perceptions may be perpetuated by clinicians having to use non-specific management resources which may be unsuitable for use with this patient group and which may not facilitate the achievement of meaningful clinical outcomes. Clinicians here reported that when they attempt to address eating and swallowing problems in patients with TMDs, they must use management techniques adopted from a range of healthcare disciplines which were not developed for use with this specific group (e.g.: dentistry, OMFS, physiotherapy, dietetics, SLT). Therefore, in order to support clinicians such as those surveyed here in their interactions with patients with TMDs who experience eating and swallowing difficulties, cohort-specific assessment tools and management resources must be developed and clinically disseminated.

Finally, a theme which emerged from analysis of the qualitative data was the need for greater MDT collaboration during the management of eating and swallowing problems in patients with TMDs, and the uncertainty that surrounds current interactions. Surveyed professionals indicated that they consider a range of eating and swallowing specific parameters to be important clinical outcomes (e.g.: improved swallowing, chewing, and oral intake), and that 38% and 21% of those surveyed want to increase their liaison with SLTs and dietitians, respectively. However, qualitative comments indicated uncertainty regarding the most appropriate method of collaboration. It is therefore suggested that these findings should inform the need for future research into the expansion of typical TMD MDTs to include professionals with specialist skills in the management of both eating and swallowing problems, such as the SLT and dietitian.

Study Limitations

To begin, the survey used here was initially piloted with SLTs, although these were not the target participants. Therefore, terms used in the survey (e.g.: “VFSS” or “swallow exercises”) which are familiar to SLTs may not be known to clinicians with dental training. This may have resulted in questions being inappropriate for use with these clinicians, with potential impact on findings. However, the primary limitation here was the small sample which was potentially unrepresentative of the overall target population, with no recruitment of GDPs, who are the primary professionals from whom patients with TMDs seek treatment. Therefore, future research recruiting a larger and more diverse group of clinicians working in this field is warranted. A greater number of participants were recruited to Group 1 using convenience sampling techniques at a national conference in comparison to the online methods used with Group 2. As such, this data may inform the selection of sampling and recruitment techniques in future research in this field.

Recommendations

As discussed, the sample for this survey was small which may impact the external validity of findings. As such, the recruitment of a larger group of clinicians who are more representative of the overall target group is warranted. It is also recommended that research into the epidemiology, nature, and impact of TMD-related eating and swallowing problems is conducted to determine the true significance of these issues. In addition, the development and clinical dissemination of cohort-specific management tools for use with adults with TMDs who experience eating and swallowing problems is recommended, in conjunction with investigation of the need to integrate the SLT and dietitian into future MDT structures, in order to support clinicians in their provision of care to this patient group.

3.4. Summary and Conclusions

This cross-sectional survey recruited a small, heterogeneous, sample of clinicians with backgrounds in dentistry, who had varying levels of experience in the management of eating and swallowing problems in patients with TMDs. Of the clinicians recruited, few reported involvement in the management of these issues, secondary to a lack of awareness regarding the potential for their development. Therefore, future conduct and dissemination of research on these issues is recommended. In addition, negative views regarding overall standards of care provided to these patients were reported by surveyed clinicians who had specialist experience in the management of TMD-related eating and swallowing problems. It is hypothesised that the lack of appropriate clinical tools available for use with these patients may act as a barrier to effective management, which therefore suggests the need to develop cohort-specific resources. Finally, the need to expand typical TMD MDTs was suggested here, with recommendations to include the SLT and dietitian in future clinical and research contexts within this field.

Chapter Four: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

4.0. Introduction

The findings of Chapter 3 suggested that due to a lack of awareness of the potential for eating and swallowing problems to develop in adults with TMDs, clinical management of these issues may be currently limited. Clinicians in this study indicated that the lack of available research on these problems contributed to their low levels of awareness. Therefore, in order to examine the available research on eating and swallowing problems in adults with TMDs, a systematic review and meta-analysis of available evidence was conducted here(246) (see Appendix 4).

4.1. Methods

The methods used to conduct this study will be discussed in subsequent sections with focus on: study design, eligibility criteria, search methods, and data extraction and analytical techniques.

Study Design

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA)(247) and Guidelines for Meta-Analyses and Systematic Reviews of Observational Studies (MOOSE)(248) directed the conduct of this systematic review. The protocol was prospectively published on the University of York Centre for Reviews and Dissemination Prospero database (Registration number: CRD42016050846)(249).

Eligible Studies

Randomised and non-randomised, published and unpublished reports investigating the prevalence of eating and swallowing problems in adults with TMDs were eligible for inclusion, with no language, geographic, or date limitations. Case reports were excluded due to their low levels of evidence(250).

Eligible Participants

Participants aged 18 years and older presenting to any location/setting, with signs and/or symptoms of TMD-related eating and swallowing problems were included, if their presenting TMDs were assessed using either the DC/TMD(15) or RDC/TMD classification systems(148), with no disease duration, severity, or age of onset limitations. Studies were excluded if participants presented with comorbid conditions affecting mandibular functioning, for example: head and neck cancer, trauma, or neurological injuries impacting on typical orofacial structure and functioning(251). Studies were also excluded if participants presented with congenital orofacial malformations(252). Finally, participants were excluded if they had a history of RA, as this condition will be investigated separately later in this dissertation (see Section 3).

Outcomes of Interest

Primary outcomes were:

1. Impaired mastication and swallowing as reported subjectively and/or detected through clinical examination, IROMS, interviews, questionnaires, and/or imaging techniques;
2. Masticatory pain as reported via interviews, questionnaires, or subjective scales; and
3. Masticatory fatigue as reported via interviews and questionnaires, or detected via clinical examination, or EMG assessment.

The secondary outcome was unintentional weight loss as reported subjectively and/or detected via the use of IROMs.

Search Strategy

A systematic search strategy which accounted for and encompassed search filters, medical subject headings, and key-text terms was developed in conjunction with TCD librarians (see Appendix 5). Only human trials were included, with no publication date or language restrictions. The databases searched from inception to October 2016 with an independent reviewer were: EMBASE, PubMed, CINAHL, Web of Science, Elsevier Scopus, Science Direct, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. Independent hand-searches of the proceedings of the annual scientific meetings of the European Society for Swallowing Disorders (published in *Dysphagia*), the Dysphagia Research Society (published in *Dysphagia*), and the International Association for Dental Research (published in the *Journal of Dental Research)* were conducted. Hand-searches of the reference lists of included studies and searches of the Google Scholar database were also conducted to identify records not indexed in the directories initially searched.

Data Extraction Process and Data Items

The Joanna Briggs Institute (JBI) data extraction form which is specialised for use in the analysis of prevalence studies was used to extract data(253) (see Appendix 6). Data was extracted on study design, setting and location, participant demographics, outcome measurement and data sources, prevalence, and statistical analysis, among other parameters. A third independent reviewer not involved in data extraction was available to mediate disputes if they occurred. Missing/unclear data was addressed via the researcher contacting primary authors of studies published within the previous 10 years. The figure of 10 years was chosen to accommodate the usual 5 year research retention period and to avoid the exclusion of studies which were published more than 5 years ago, but primary authors had retained records for retrospective analysis (L. Zgaga, Personal communication, February 26, 2016). Records were excluded following no response to 2 contact attempts.

Assessment of Methodological Quality

To assess the methodological quality of included studies, 2 independent reviewers utilised the Downs and Black Checklist Tool(254) which investigates the methodological quality of randomised and non-randomised clinical trials of healthcare interventions (see Appendix 7). A hybrid version of Boyle's(255) method of evaluating prevalence studies and the JBI Critical Appraisal Checklist for Reporting Prevalence Data(256) was also used as a supplementary method to pilot its use (see Appendix 8). These tools were amalgamated as both are correlated across all assessment domains, yet the JBI tool, unlike the Boyle method, does not investigate the presence of confidence intervals (CI), which is a key tenet of statistical rigour.

Summary Measures and Synthesis of Results

Included studies were first described descriptively, with subsequent statistical analysis. Fixed and random effects meta-analyses of prevalence estimates were conducted using Microsoft Excel (Microsoft, Richmond, WY, USA) and the MedCalc Systems for Windows, version 15.0 (MedCalc Software, Ostend, Belgium)(257). Prevalence figures were presented using 95% CIs, with forest plots constructed for all estimates.

4.2. Results

The results of this study will be presented in subsequent sections with attention to the studies identified, characteristics of participants, and results of the meta-analysis.

Study Identification

A total of 10248 results were retrieved (see Figure 16). All records were exported to the Zotero reference management software (Zotero Software, George Mason University, USA). Following the exclusion of 4245 duplicates and 5381 records based on their titles, abstract, and/or keywords, 2 independent reviewers examined 622 full-text records, with a third reviewer available to independently mediate disputes, if required. At this stage, 617 of these full-text records were excluded. Supplementary Google Scholar searches identified 13 further eligible studies, following extensive author contact. An additional eligible article was identified from reference list searches and 1 further article was identified via author contact.

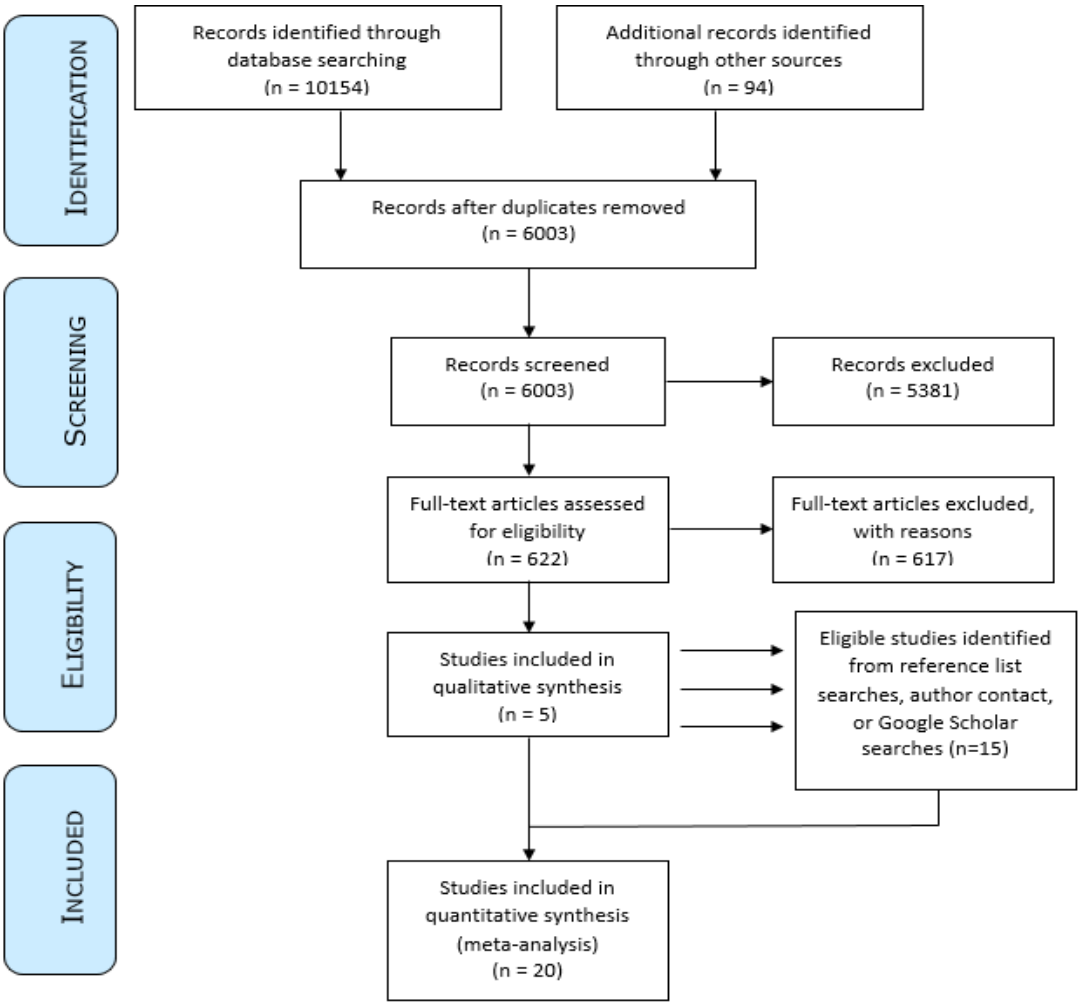


Figure 16: PRISMA Diagram

In total, during both foundational and supplementary searches, 291 contact attempts were made regarding 155 potentially eligible records. For 117 of these studies, missing data was sought, while 38 communications related to article access. Contact led to 12 eligible studies, the exclusion of 98 studies due to no response, 24 due to insufficient data, 10 studies due to inability to access records, 5 due to inappropriate research objectives, 3 due to use of inappropriate outcome measurement tools, and 3 due to inappropriate participants. Ultimately, 20 studies satisfied the eligibility criteria, had data extracted, and were included in the final analysis.

Participant Demographics

Data regarding 1581 participants were extracted across 20 studies, with the pooled age range being 18-88 years of age. Four included studies did not provide mean ages of eligible participants (20%), while 12 eligible studies did not provide details regarding age ranges (60%). Studies involving a total of 1136 females and 351 males were included (3.23:1 / female: male), while 2 studies did not provide details on gender (see Table 13).

Table 13: Characteristics of Included Studies

Citation	Year of publication	Region from which participants were recruited	Setting from which participants were recruited	Period of recruitment	Study design	No. of patients with TMDs studied	Female: male ratio	Mean age (SD) of patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (months)	Relevant outcome measured	Sources of assessment data	Study quality score
Baker et al., (126)	2015	Sweden	University clinic	36 months	RCT	34	10.3:1	38.9 (+- 15)	Unclear	49.1 (unclear)	Impaired swallowing: 5.88%; Impaired mastication: 20.58%	RDC/TMD, X-ray, MRI, IMMPACT questionnaire, Visual analog scale (VAS), Jaw Functional Limitation Scale-8 (JFLS-8), Graded Chronic Pain Scale (GCPS), Symptom Checklist-90-Revised (SCL-90R)	15/18
Wanman (120)	2012	Sweden	University clinic	Unclear	Case-control	108	5.23:1	40 (+-13)	Unclear	Unclear	Impaired mastication: 62.96%	RDC/TMD, subjective questionnaire, endurance tests, VAS	11/18
Mapelli et al., (118)	2016	Brazil	University clinic	Unclear	Case-control	30	9:1	30.5 (Unclear)	Unclear	59.2 (7-240)	Impaired swallowing: 0%; Impaired mastication: 76.6%	RDC/TMD, ProTMDmulti questionnaire, EMG	13/18
Foteder et al., (123)	2015	India	University hospital clinic	6 months	Cross-sectional	195	5.91:1	34.8 (+- 17.2)	Unclear	Unclear	Impaired mastication: 54.32%; Masticatory fatigue: 50.61%	RDC/TMD, patient interviews, case history, Oral Health Impact Profile-14 (OHIP-14)	12/18
Abrahamsson (117)	2013	Sweden	University hospital clinic	60 months	Case-control	90	1.37:1	22 (+- 7.4)	Unclear	Unclear	Impaired mastication: 75.2%	RDC/TMD, VAS, subjective questionnaire, self-reported masticatory ability, masticatory performance test, dental exam	16/18
Ferreira et al., (125)	2017	Italy	Specialised private practice facial pain clinic and university hospital clinic	Unclear	Case-control	12	12:0	37 (+-16)	Unclear	39 (unclear)	Impaired swallowing: 0%; Impaired mastication: 41.66%; Masticatory fatigue: 66.6%	RDC/TMD, ProTMDmulti, orofacial myofunctional evaluation with scores (OMES), near infrared spectroscopy	15/18
La Touche et al., (140)	2015	Spain	Specialised private practice facial pain clinic and	Unclear	Case-control	33	Unclear	Unclear	Unclear	Unclear	Masticatory pain: 96.38%; Masticatory fatigue: 98.79%	RDC/TMD, subjective questionnaire, VAS, Pain Catastrophizing Scale (PCS), provocation chewing test, pressure pain threshold, maximal	16/18

			public health centre									mouth opening, Neck Disability Index, Headache Impact Test-6	
Dougall et al., (143)	2012	America	General dental practice	Unclear	Descriptive observational	185	4.28:1	42.68 (unclear)	Unclear	Unclear	Masticatory pain: 89.72%	RDC/TMD, Characteristic Pain Index (CPI), GCPS, chewing performance test, Medical Outcomes Shortform-36 Status Questionnaire, SCL-90R , Beck Depression Inventory	11/16
Khawaja et al., (122)	2015	America	University clinic	Unclear	Descriptive observational	94	1.47:1	34.2 (+-12.2)	Unclear	Unclear	Impaired mastication: 56.38%	DC/TMD, Oral Behaviours Checklist (OBC), GCPS, CPI, MRI, Patient Health Questionnaire-4 (PHQ-4), Generalised Anxiety Disorder Scale	11/16
Maffei et al., (114)	2012	Unclear	Unclear	Unclear	Descriptive observational	10	1.5:1	Unclear	Unclear	Unclear	Impaired swallowing: 70%; Impaired mastication: 90%	RDC/TMD, VFSS, SLT dysphagia assessment	6/16
De Felicio et al.,(129)	2012a	Brazil	University clinic	Unclear	Case-control	30	1:0	30 (+-8)	Unclear	Unclear (6-108)	Impaired swallowing: 0%; Impaired mastication: 0%	RDC/TMD, EMG, OMES, ProTMDmulti	12/18
Da Silva et al., (127)	2011	Brazil	University clinic	11 months	Case-control	70	0.84:1	53 (unclear)	Unclear	Unclear	Impaired swallowing: 16.6%; Impaired mastication: 11.1%; Masticatory pain: 72.2%	RDC/TMD, salivia flow evaluation, xerostomia questionnaire, dental exam	12/18
Raphael & Marbach (124)	2001	America	University clinic and general dental practice	Unclear	RCT	63	1:0	33.7 (+-10.9)	Unclear	60 (UNC)	Impaired swallowing: 7.93%; Impaired mastication: 49.2%;	RDC/TMD, SCL-90, clinical exam, self-reports of pain, functional outcome assessment	16/18
Barros et al., (119)	2008	Brazil	University clinic	4 months	Cross-sectional	132	4.92:1	36.5 (+-13.5)	Unclear	Unclear	Impaired mastication: 79.51%; Masticatory fatigue: 33.73%	RDC/TMD, OHIP-14, clinical exam, Temporomandibular Index	13/16

Radke et al., (115)	2014	Unclear	Unclear	Unclear	Descriptive observational	28	1:1	34.5 (+-14.0)	Unclear	Unclear	Impaired mastication: 100%	RDC/TMD, magnetic incisor point tracking	7/16
Gonçalves et al., (128)	2011	Brazil	University hospital clinic	Unclear	Case-control	28	28:0	Unclear	Unclear	Unclear	Impaired mastication: 0%	RDC/TMD, anthropomorphic assessment, ovulation prediction test, maximum occlusal force, sieve method assessment of masticatory performance	15/18
Brandini et al., (121)	2011	Australia	Unspecified hospital	Unclear	Case-control	15	15:0	31.3 (+-10.8)	Unclear	Unclear	Impaired mastication: 60%	RDC/TMD, chewing task, numerical rating scale-II, Pain Self-efficacy Questionnaire, Fear-Pain Questionnaire-III, Disease Activity Score-44(DAS-44), PCS	13/18
Reißmann et al., (116)	2007	Germany	University clinic	66 months	Case-control	312	3.16:1	38.6 (+-15.6)	Unclear	Unclear	Impaired mastication: 82.07%; Masticatory pain: 68.53%; Masticatory fatigue: 45.91%	RDC/TMD, German version of OHIP, GCPS, Beschwerden-Liste, the Center for Epidemiologic Studies Depression Scale	10/18
Gavish et al., (141)	2000	Israel	University clinic	Unclear	Prospective cohort	49	2.76:1	29.2 (+-7.8)	Unclear	Unclear	Masticatory pain: 83.67%;	RDC/TMD, clinical exam, experimental chewing task, palpation, VAS	16/18
Michelotti et al., (139)	2002	Italy	University clinic	Unclear	RCT	63	Unclear	Unclear	Unclear	Unclear	Masticatory pain: 100%	RDC/TMD, anamnestic and clinical scores, measures of pressure pain thresholds, pain during gum chewing, and spontaneous pain, VAS	4/18

The symptoms with which eligible participants presented are shown in Table 14. The discrepancy between the number of participants recruited (n=1581) and the total number of symptom categories presented below (n=1631) is due to some studies providing classifications for both TMJs, while others classified patients according to the unilateral TMJ which was most impaired.

Table 14: Symptomatic Classification of Participants

Symptomatic Classification	Osteoarthrosis	DDWR + MFP	DD/OA	MFP + OA + arthralgia	DDWOR + arthralgia	DDWR + myalgia	Myalgia	OA	MFP+ DDWR / OA	DDWOR	Arthralgia	DDWR	MFP
Number of participants	13	30	32	34	34	40	58	59	91	95	190	275	672

The most frequently reported symptoms were: MFP (n=672/ 41.2%), DDs (DDWR: n=275/16.9%; DDWOR: n=95/5.8%), and arthralgia (n=190/ 11.6%). Some participants were classified as presenting with mixed symptom profiles (n=229/14%), with MFP-DD/OA being the most frequent (n=91/5.6%). Two studies provided unclear categorizations, classifying participants as presenting with either DD or OA (n=32)(143), or MFP combined with DDWR or OA (n=91)(140).

Characteristics of Included Studies

Half of included records (n=10) were case-control studies, while 20% (n=4) were descriptive observational studies, 15% (n=3) were RCTs, 10% (n=2) were cross-sectional studies, and 5% (n=4) were prospective cohort studies. Study locations included Europe (n=7/35%), South America (n=5/25%), North America (n=3/15%), Asia (n=1/5%), Australia (n=1/5%), and Israel (n=1/5%). Two studies did not specify location (10%)(114,115). Settings varied, with most conducted in university clinics (n=10/50%), university teaching hospitals (n=3/15%), and dual settings (n=3/15%). General dental practices (n=1/5%) and unspecified hospital settings (n=1/5%) were the settings of 2 studies. It was unclear where 2 studies were conducted(114,115).

Data sources varied, with 19 studies (95%) utilising the RDC/TMD(148) and 1 study (5%)(122) using the DC/TMD system(15). IROMs were employed in 6 studies (30%), including X-rays, MRI, EMG, VFSS, near infrared spectroscopy, and magnetic incisor point tracking. Assessments of mastication were used in 8 studies (40%). VAS were used in 6 studies (30%), while subjective questionnaires were used in 16 studies (80%), with a range of 24 such tools being employed (see Table 13).

Assessment of Methodological Quality of Included Studies

Reviewers independently reached 100% consensus regarding assessments of methodological quality. According to ratings assigned using the Downs and Black Checklist(254) (see Tables 15, 16, and 17), studies which recruited a comparison group were awarded an average of 12.4 out of a possible 18 points, which is an average rating of moderate quality. Studies which did not recruit a comparison group were awarded a mean score of 9.6 out of a possible 16, which is an average rating of fair quality. Only 1 study was deemed to be of poor quality, yet only an abstract was

available for this record, limiting assessment(139). Methodological risk of bias was also assessed using the hybrid Boyle-JBI scale(255,256). Ratings awarded using both the Downs and Black Checklist Tool and Boyle-JBI scale were highly correlated (see Appendix 9).

The main items responsible for lower ratings of methodological quality were:

- Inadequate or unclear adjustment for confounding factors (n=10/50%);
- Inadequate/lack of descriptions of whether participants who were prepared to participate were representative of the entire population (n=12/60%); and
- Inadequate/lack of description of patients who were lost to follow-up (n=12/60%).

Items contributing to positive ratings included:

- Clear statements of hypothesis/aims/objectives and main findings (n=20/100%);
- Explicit descriptions of the characteristics of patients, including the provision of explicit inclusion and exclusion criteria (n=17/85%);
- Use of appropriate statistical tests to assess main outcomes (n=19/95%); and
- Use of accurate and valid outcome measures in assessment (n=19/95%) (see Table 17).

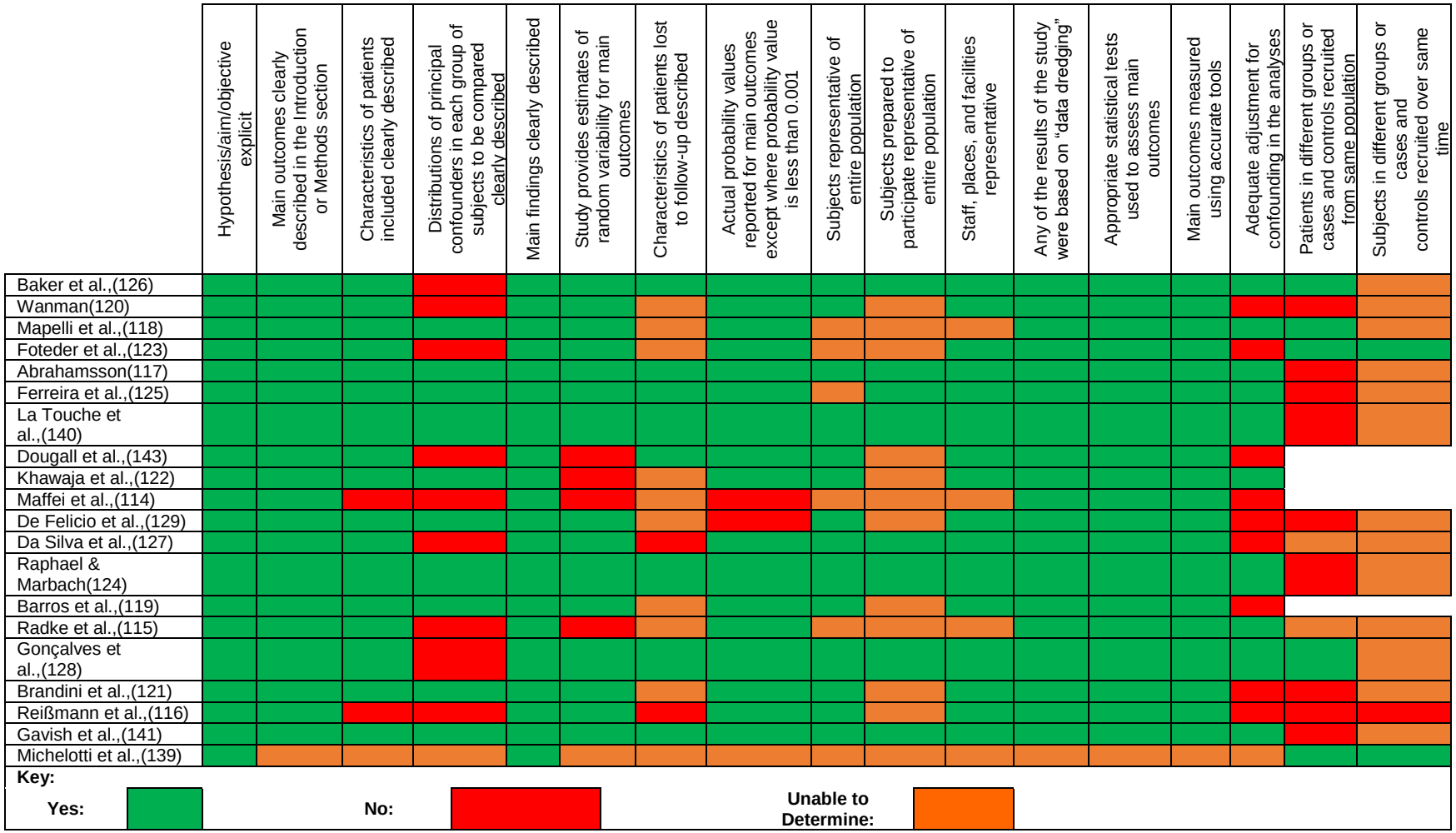
Table 15: Downs and Black Checklist Scoring of Included Studies

Study Name	Score Awarded	Comparison Group	Rating Awarded
Baker et al.,(126)	15	Yes	Good quality
Wanman(120)	11	Yes	Moderate quality
Mapelli et al.,(118)	13	Yes	Moderate quality
Foteder et al.,(123)	12	Yes	Moderate quality
Abrahamsson(117)	16	Yes	Good quality
Ferreira et al.,(125)	15	Yes	Good quality
La Touche et al.,(140)	16	Yes	Good quality
Dougall et al.,(143)	11	No	Moderate quality
Khawaja et al.,(122)	11	No	Moderate quality
Maffei et al.,(114)	6	No	Fair quality
De Felicio et al.,(129)	12	Yes	Moderate quality
Da Silva et al.,(127)	12	Yes	Moderate quality
Raphael & Marbach(124)	16	Yes	Good quality
Barros et al.,(119)	13	No	Good quality
Radke et al.,(115)	7	No	Fair quality
Gonçalves et al.,(128)	15	Yes	Good quality
Brandini et al., (121)	13	Yes	Moderate quality
Reißmann et al.,(116)	10	Yes	Moderate quality
Gavish et al.,(141)	16	Yes	Good quality
Michelotti et al.,(139)	4	Yes	Poor quality

Table 16: Downs and Black Checklist Rating Criteria

Descriptor	Criteria for Studies with Comparison Group	Criteria for Studies with no Comparison Group
Poor Quality	0-4	0-3
Fair Quality	5-9	4-7
Moderate Quality	10-14	8-11
Good Quality	15-18	12-16

Table 17: Downs and Black Methodological Quality Risk of Bias Table



Prevalence of TMD-related Eating and Swallowing Problems

Impaired mastication was reported in 16 studies (n=1064)(114–129), with this prevalence estimated to be 52.67% (95% CI: 37.182-67.91%) (see Figure 17).

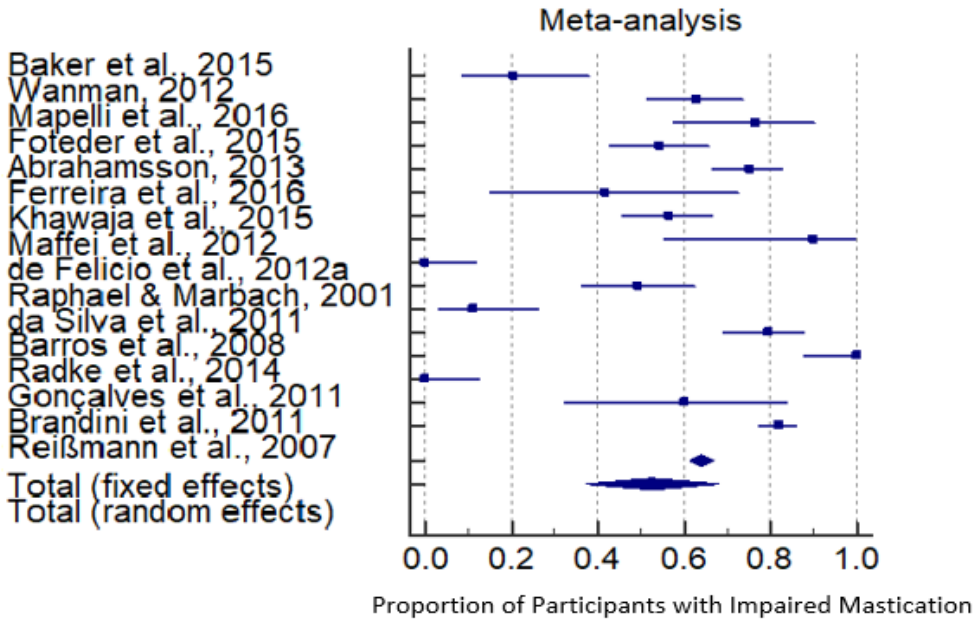


Figure 17: Forest Plot of Prevalence of Impaired Mastication

Masticatory pain was reported in 6 studies (n=734)(116,127,139–141,143), with this prevalence estimated to be 87.38% (95% CI: 74-96.39% (see Figure 18).

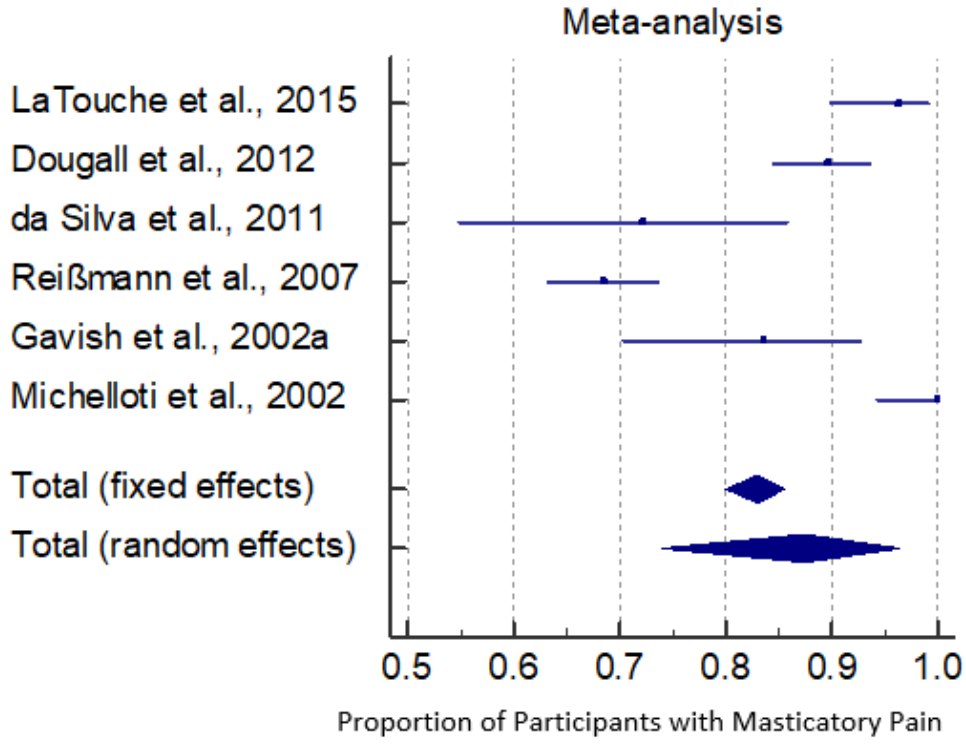


Figure 18: Forest Plot of Prevalence of Masticatory Pain

Masticatory fatigue was reported in 5 studies (n=577)(116,119,123,125,140), with this prevalence calculated to be 61.95% (95% CI: 34.16-86.03%) (see Figure 19).

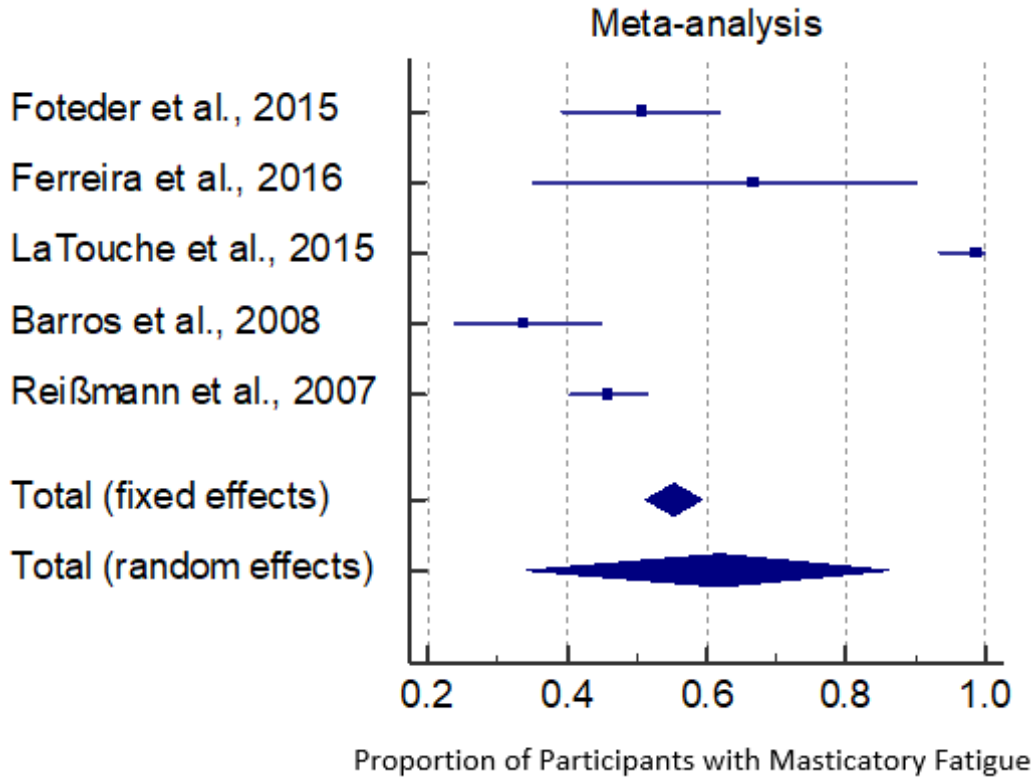


Figure 19: Forest Plot of Prevalence of Masticatory Fatigue

Based on data from 7 studies (n=215)(114,118,124–127,129), the prevalence of impaired swallowing was estimated to be 9.3% (95% CI: 2.1-20.86%) (see Figure 20).

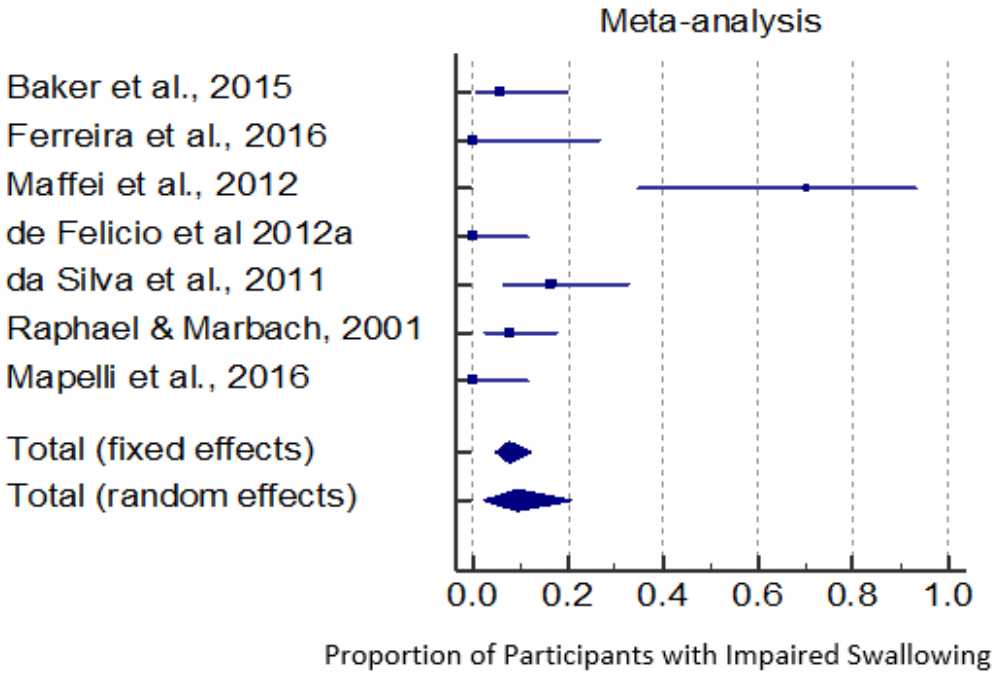


Figure 20: Forest Plot of Prevalence of Impaired Swallowing

No eligible records were identified which investigated weight loss in the cohort of interest.

4.3. Discussion

This systematic review and meta-analysis highlighted that eating and swallowing problems may develop secondary to masticatory impairments in adult patients with TMDs, although this condition has previously received limited clinical and research attention. Impaired mastication was estimated to be experienced by approximately 53% of adult patients presenting with TMDs in this study. However, only 50% of eligible studies which reported figures on impaired mastication collected data using chewing performance or endurance tasks, with the remaining studies relying on subjective patient reports(115,116,119,123,124,126,127). As such, there is the potential for the under-identification of perceptually mild masticatory impairments when only subjective data is collected.

Masticatory pain was also estimated to be experienced by 87% of individuals in this study. However, the precise pathophysiology of this pain across TMD symptom classifications is unknown, with no cohort-specific assessment tools available to determine risk factors for masticatory pain in adults with TMDs. Consequentially, cohort-specific evidence-based compensatory strategies or rehabilitative interventions have not been developed for this issue. In addition, masticatory fatigue was present in approximately 62% of individuals with TMDs, as measured using primarily subjective measures(116,119,123,125,140). Individuals with chronic pain and central sensitization conditions frequently report fatigue as a primary determinant of well-being, with chronic fatigue being cited as a mediating factor in the relationship between functioning, pain, and HRQOL(258). However, despite the perceived significance of this symptom, masticatory fatigue attributed to TMDs has been minimally investigated, and no eligible studies reported prevalence rates using EMG to measure indices of muscle fatigue and reduced endurance and exercise tolerance, thus potentially reducing the reliability and validity of findings. In light of these criticisms, it is advised that future research adopts a hybrid approach utilising both subjective outcome measurement tools and IROMs to investigate the patient's experience while also ensuring the psychometric validity and reliability of findings.

The primary outcome under investigation here, impaired swallowing, was detected in 9.3% of included participants, with this thought to develop secondary to impaired mastication. However, it is hypothesised that the true prevalence of this problem may be higher than rates presented here, as studies which were eligible for inclusion were heterogeneous. Also, the method by which swallowing was assessed in primary studies may have influenced the overall prevalence estimate, with most eligible studies using subjective assessments which had varied psychometric properties and which were unspecified in certain studies(114,124,127). The reliance on unspecified and varied subjective measures emphasizes the need for both improvements in the reporting of the details and psychometric properties of subjective outcome measurements used, and the frequency of use of IROMs within primary studies. Finally, theoretical issues may also impact negatively on the homogeneity, validity, and reliability of research findings in this field. For

example: differing theoretical definitions of what constitutes a diagnosis of swallowing difficulties in this patient group have been adopted, and many studies which have investigated this parameter have not specified their operational definition of “impaired deglutition” (e.g.: impaired transit of the bolus from the oral to the pharyngeal cavity, impaired triggering of the pharyngeal swallow, or impaired protection of the airway, etc). As such, in critical analysis of studies conducted in this field, researchers are limited in their ability to construct a cohesive picture of findings. As eating and swallowing problems caused by a range of aetiologies have documented effects on functioning, levels of activity and participation, and HRQOL(259), it is essential that these issues receive greater attention within the field of TMD research in the future.

Finally, no eligible articles reported data on the prevalence of weight loss in adults with TMD-related eating and swallowing problems. Weight loss is a commonly cited consequence of impaired eating and swallowing in non-TMD patient groups, with documented systemic consequences at cellular, muscular, neurological, cognitive, functional, and psychological levels(260). As such, it is advised that prospective investigations are conducted to determine the true prevalence, nature, and impact of this issue, and to therefore understand its clinical significance and need for intervention.

Study Limitations

One limitation of this study is that few records satisfied the inclusion criteria. For example: while many primary studies reported that patients presented with TMDs, few provided sufficient demographic information (e.g.: gender, mean age, DDWR, MFP, etc.) to allow for statistical stratification, with information also unavailable on author contact attempts. This resulted in the forced exclusion of many studies which may have influenced ultimate findings. Therefore, results are derived from a limited, and potentially unrepresentative, cohort of heterogeneous primary studies. As such, it is recommended that large-scale psychometrically valid and reliable epidemiological research is conducted to address these concerns. A further limitation is the lack of studies which utilised IROMs as sources of assessment data, as the reliance on subjective measures alone may introduce observer, recall, and/or detection bias. As such, it is recommended that future studies employ a combination of both subjective patient-report and IROMs.

Recommendations

As this study highlighted the presence of eating and swallowing problems in adults with TMDs within previously published research, it is recommended that prospective epidemiological research is conducted to both further our understanding of this condition and to inform the need for future clinical developments in this field. It is also advised that cohort-specific assessment tools are developed for use with this patient group within future research and clinical contexts.

4.4. Summary and Conclusions

This study highlighted that eating and swallowing problems are reported within the literature to be experienced by adults presenting with TMDs. This finding contrasts the earlier reported lack of professional awareness of these problems, and suggests that patients with TMDs may require specific clinical management for these issues to avoid the development of chronicity. This study has also identified methodological limitations within the available literature which may impact negatively on both the internal and external validity of results, and has therefore indicated the need for future prospective research investigating the epidemiology, nature, impact, and management of TMD-related eating and swallowing problems.

Chapter Five: The Prevalence, Nature, and Management of Eating and Swallowing problems in Adults with Temporomandibular Disorders: Findings from an Irish Cohort

5.0. Introduction

Findings from Chapter 4 suggest that eating and swallowing problems are reported by adults with TMDs (see Section 4.2.). Yet, earlier results indicated that the perceived significance of these issues is low among surveyed professionals working within the Irish healthcare system, leading to limited management of these issues (see Section 3.2.). It is hypothesised that if these problems are not addressed during TMD care, they may subsequently impact on functioning, nutrition, and HRQOL. However, minimal prospective research has been previously conducted on their prevalence, nature, or management within either an international or Irish context. Therefore, a cross-sectional patient survey was conducted here to investigate the epidemiology, nature, and typical management of eating and swallowing problems in adult patients presenting with TMDs (see Appendix 10). Also, in response to the recommendations of Chapter 4, data was gathered here using a newly developed cohort-specific assessment tool (see Section 4.3.).

5.1. Methods

The methods used to conduct this study will be discussed in the following sections.

Study Design

This study implemented a cross-sectional prospective survey design in order to examine the prevalence, nature, and management of TMD-related eating and swallowing problems in adult patients. Ethical approval was granted by the St. James's Hospital (SJH)/Tallaght University Hospital (TUH) Research Ethics Committee to conduct this research (see Appendix 11).

Research Settings

Consecutive adult patients presenting to Oral Surgery and OMFS clinics in the Dublin Dental University Hospital (DDUH) and OMFS clinics in the National Maxillofacial Unit (NMU), SJH, for TMD treatment were recruited for involvement in this study over the 6-month period in 2016 (July 2016-December 2016). The DDUH is an academic dental teaching hospital and provides primary, secondary and tertiary specialist dental care, while the NMU is the national centre for the provision of both conservative and surgical treatment for oral and maxillofacial pathology. The unit also operates an outpatient clinic in which patients are seen at both pre- and post-operative stages of care and provides care to patients with facial deformities (congenital or post-traumatic), oral and head and neck cancer, orofacial pain and TMDs, and implantology and dentoalveolar/orthodontic surgical needs(261).

Participants

Eligible participants were adult patients (aged 18 years and older) of any sex, race, or severity seeking TMD treatment at the sampling locations during the study period, who were assessed using the DC/TMD(15), or RDC/TMD classification systems(148). Participants were excluded if they were aged below 18 years, or if they presented with a history of relevant comorbid conditions affecting mandibular functioning, such as facial trauma, head and neck cancer, neurological pathology, or congenital conditions affecting the orofacial region(262,263). It was unknown the number of potentially eligible participants presenting to sampling locations over a 6-month period. Therefore, it was not possible to prospectively calculate sample size prior to study initiation.

Materials Used

A new cohort-specific structured interview tool was developed in order to investigate the domains of interest (see Appendix 12). The Temporomandibular Disorder Eating, Drinking, and Swallowing Scale (TEDSS) was used here to investigate the presence and nature of these difficulties and their management in adults with TMDs. In order to survey the specific aetiologies of presenting TMDs, the TEDSS included a Symptomatic Classification subscale including the most common TMJ and masticatory muscle symptoms abstracted from the DC/TMD(15). The DC/TMD classification system reliably differentiates between the most frequent TMD symptoms (sensitivity ≥ 0.86, specificity ≥ 0.98)(15). Participants here indicated which TMD symptoms they presented with, including: arthralgia, subluxation, headache attributed to TMD, myalgia, MFP, DDs, and DJD(15). An “other” and “unknown” section was also provided.

In addition, a Signs and Symptoms subscale was adapted from the JFLS(264) and the DC/TMD(15). The JFLS is a self-report measure which assesses difficulties related to mastication and jaw mobility, among other facets(264,265). In total, 10 items relating to chewing, swallowing, weight loss, and diet modification were extracted from the Mastication sub-scale of the JFLS, which has established psychometric properties as a stand-alone scale (item reliability: 0.95; person reliability: 0.86; Cronbach’s alpha: 0.83)(265). The original interval scale scoring system was also modified to a binary “yes”/”no” system as information was sought on the presence/absence of eating and swallowing problems.

Finally, a Management subscale was also included which sought information on intervention strategies the participant had previously used to manage symptoms of TMD-related eating and swallowing problems. This subscale was developed via literature review of commonly used TMD, eating and swallowing problems, and chronic pain management techniques.

Data Collection

The sampling method employed in data collection was convenience sampling with a consecutive paradigm. A consultant OMFS working in both DDUH and the NMU acted as a gatekeeper in the identification of potential participants and the provision of access to clinical sites and patient lists. On their presentation to the sampling locations, all patients who were identified as potentially

eligible participants were provided with a PIL (see Appendix 13) and the research survey (see Appendix 12). Completion of the research survey took approximately 5 minutes.

Statistical Analysis

Descriptive statistics were used to summarize all demographic data. Age, sex, and symptom-specific prevalence alongside overall rates of eating and swallowing problems were also descriptively calculated. Statistical analysis was also completed, with non-parametric Mann-Whitney U and post-hoc Kruskal-Wallis tests with Bonferroni's correction conducted in conjunction with the calculation of Spearman's rank correlation coefficient.

5.2. Results

In total, 182 surveys were disseminated to patients presenting to clinical sites during the study period, with 178 ultimately participating, yielding a 98% response rate.

Respondent Demographics

Respondent characteristics are described in Table 18.

Table 18: Demographics of Survey Sample

Characteristics	Overall Sample	Arthralgia	Myalgia	MFP	Headache attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Age (years)											
Mean (SD)	43.196 (+- 16.79)	56.25 (+- 13.41)	43.55 (+- 15.66)	50.73 (+- 17.64)	40 (+- 7.93)	35.71 (+- 12.73)	38.03 (+- 14.06)	54.66 (+- 21.36)	61 (+- 11.34)	39.6 (+- 28.69)	41 (+- 14.95)
Median	43	55.5	44	49	43	36	36	67	62	32	39
Range	18-92	40-81	18-70	23-92	31-46	18-61	18-65	30-67	43-72	18-88	18-65
Gender (n)											
Male	36	2	3	3	1	9	5	1	1	1	10
Female	142	6	17	32	2	38	25	2	5	4	11

The overall age range was 18-92 years (mean: 43/ SD: +-17). The sex profile of the sample was 80% female (n=142) and 20% male (n=36), indicating a female: male ratio of 4:1. TMJ-related disorders were experienced by half of all participants (n=91/51%), and predominantly by females (females: n=74/ males: n=17). DDs were the most frequently reported TMJ-related symptoms, with DDWR and DDWOR experienced by 26% (n=47) and 17% (n=30), respectively. Masticatory muscle disorders were reported by 66 participants (37%), with high levels of female representation (females: n=57 / males: n=9). MFP was the most frequent masticatory muscle disorder (20% of the overall sample (n=35)). The aetiology of TMDs were unknown in 12% (n=21) of all cases.

Symptoms of Eating and Swallowing Problems

Most participants (n=176/99%) reported at least 1 sign/symptom of an eating or swallowing problem (see Table 19). Depending on consistency, difficulties chewing hard/crunchy food were

present in 89% of participants (n=159), while difficulties chewing soft food were reported by 58% (n=104). Difficulties chewing food that requires minimal effort was reported by 24% (n=42). Impaired mastication across consistencies was reported to a greater degree by participants with TMJ disorders. Pain on mastication was reported by 90% (n=160), while masticatory fatigue was experienced by 78% (n=139). Difficulty swallowing was reported by 33% (n=59) of all participants. Dysphagia for liquids was reported by 28% (n=49), which may be related to difficulties opening the mouth wide enough to drink from a cup/glass. Weight loss was experienced by 26% (n=47) of respondents.

Table 19: Investigated Symptoms of Eating and Swallowing Problems

Symptoms	Overall Sample	Arthralgia	Myalgia	MFP	Headache attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Difficulty swallowing	33.14% (59)	37.5% (3)	20% (4)	40% (14)	0% (0)	34.09% (15)	23.4% (11)	66.6% (2)	0% (0)	80% (4)	28.5% (6)
Difficulty drinking	27.52% (49)	37.5% (3)	20% (4)	40% (14)	0 (0%)	27.65% (13)	23.33% (7)	66.6% (2)	0 (0%)	80% (4)	9.52% (2)
Difficulty chewing hard/crunchy food	89.32% (159)	75% (6)	90% (18)	94.28% (33)	66.6% (2)	95.74% (45)	90% (27)	100% (3)	83.33% (5)	100% (5)	71.42% (15)
Difficulty chewing soft food	58.42% (104)	62.5% (5)	45% (9)	74.28% (26)	0% (0)	55.31% (26)	60% (18)	100% (3)	50% (3)	80% (4)	42.85% (9)
Difficulty eating food that requires little/no chewing	23.59% (42)	25% (2)	15% (3)	31.42% (11)	0% (0)	25.53% (12)	23.3% (7)	0% (0)	33.3% (2)	40% (2)	14.28% (3)
Pain on chewing	89.88% (160)	75% (6)	85% (17)	97.14% (34)	66.6% (2)	97.87% (46)	86.66% (26)	100% (3)	50% (3)	80% (4)	90.47% (19)
Tiredness on chewing	78.08% (139)	75% (6)	60% (12)	90% (27)	100% (3)	78.72% (37)	86.66% (26)	100% (3)	66.6% (4)	100% (5)	76.19% (16)
Weight loss	26% (47)	12.5% (1)	20% (4)	34% (12)	0% (0)	17.02% (8)	40% (12)	66.6% (2)	16.6% (1)	0% (0)	33.3% (7)

Participants also reported additional problems using the “other” section of the TEDSS. These were stratified into 5 broad categories, including: masticatory, oromotor, pain, audiological, and psychosocial symptoms (see Table 20). Half of participants reported unilateral (n=98/55%) or slow mastication (n=88/49%), while a fifth (n=31/17%) reported being able to masticate only soft, pre-processed foods and subsequently unintentionally gaining weight. The psychosocial impact of eating and swallowing problems was also highlighted, with 44% (n=78) experiencing anxiety and/or embarrassment regarding their eating and swallowing problems, with data trends suggesting that this a symptom experienced most frequently by those with masticatory muscle disorders. Also, almost half of participants (n=74/42%) reported avoiding all social interaction when their eating and swallowing problems were most severe.

Table 20: Other Symptoms associated with Eating and Swallowing Problems

Other Symptoms		Overall Sample	Arthralgia	Myalgia	MFP	Headache attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Masticatory Symptoms	*Slowed Mastication*	49.43% (88)	62.5% (5)	35% (7)	68.57% (24)	0% (0)	63.82% (30)	46.66% (14)	66.6% (2)	16.6% (1)	80% (4)	4.76% (1)
	Unilateral mastication	55.05% (98)	75% (6)	45% (9)	71.4% (25)	0% (0)	76.59% (36)	53.3% (16)	66.6% (2)	16.6% (1)	60% (3)	0% (0)
	Restricted to eating soft nutritionally-imbalanced foods and gaining weight	17.41% (31)	0% (0)	15% (3)	34.28% (12)	0% (0)	19.14% (9)	16.66% (5)	0% (0)	0% (0)	20% (1)	4.76% (1)
Oromotor symptoms	*Drooling*	3.37% (6)	0% (0)	5% (1)	5.71% (2)	0% (0)	2.12% (1)	0% (0)	0% (0)	0 (0%)	20% (1)	4.76% (1)
	Slurred speech	33.7% (60)	62.5% (5)	15% (3)	40% (14)	0% (0)	42.55% (20)	33.3% (10)	33.3% (1)	16.6% (1)	40% (2)	19.04% (4)
	Painful speech	43.82% (78)	62.5% (5)	30% (6)	51.42% (18)	0% (0)	55.31% (26)	46.6% (14)	33.3% (1)	16.6% (1)	60% (3)	19.04% (4)
	Difficulties laughing	43.25% (77)	37.5% (3)	20% (4)	57.14% (20)	0% (0)	61.7% (29)	53.3% (16)	33.3% (1)	16.6% (1)	60% (3)	0% (0)
	Difficulties singing	39.32% (70)	50% (4)	15% (3)	54.28% (19)	0% (0)	55.31% (26)	40% (12)	33.3% (1)	16.6% (1)	60% (3)	4.76% (1)
	Difficulties kissing	11.79% (21)	0% (0)	10% (2)	11.42% (4)	0% (0)	14.89% (7)	23.3% (7)	0% (0)	0% (0)	20% (1)	0% (0)
	Bruxism	56.17% (100)	50% (4)	35% (7)	71.42% (25)	0% (0)	74.46% (35)	63.33% (19)	66.6% (2)	16.6% (1)	100% (5)	4.76% (1)
	Occlusal changes	8.98% (16)	25% (2)	15% (3)	8.57% (3)	0% (0)	4.25% (2)	13.3% (4)	0% (0)	0% (0)	0% (0)	9.52% (2)
Pain symptoms	*Migraines/headaches*	39.88% (71)	37.5% (3)	35% (7)	48.57% (17)	100% (3)	48.93% (23)	46.6% (14)	33.3% (1)	0% (0)	20% (1)	9.52% (2)
	Auricular pain	32% (57)	25% (2)	25% (5)	42.9% (15)	0% (0)	46.8% (22)	33.3% (10)	33.3% (1)	0% (0)	20% (1)	4.76% (1)
Audiological symptoms	*Hearing loss*	5.1% (9)	0% (0)	0% (0)	2.9% (1)	0% (0)	6.4% (3)	10% (2)	33.3% (1)	0% (0)	0% (0)	9.52% (2)
	Tinnitus	5.1% (9)	0% (0)	5% (1)	2.9% (1)	0% (0)	6.4% (3)	10% (2)	33.3% (1)	0% (0)	0% (0)	4.76% (1)
Psychosocial symptoms	*Difficulties concentrating*	23% (41)	12.5% (1)	10% (2)	40% (14)	0% (0)	29.8% (14)	20% (6)	66.6% (2)	0% (0)	20% (1)	4.76% (1)
	Anxious/embarrassed about people noticing difficulties	43.82% (78)	62.5% (5)	25% (5)	51.42% (18)	0% (0)	44.7% (21)	56.7% (17)	33.3% (1)	0% (0)	20% (1)	23.8% (5)
	Avoidance of social situations	41.57% (74)	62.5% (5)	25% (5)	48.57% (17)	0% (0)	46.8% (22)	56.7% (17)	66.6% (2)	0% (0)	20% (1)	23.8% (5)

	Avoidance of occupational situations	26.4% (47)	37.5% (3)	15% (3)	42.9% (15)	0% (0)	29.8% (14)	33.3% (10)	33.3% (1)	0% (0)	20% (1)	0% (0)
	Relationship difficulties	30.9% (55)	37.5% (3)	10% (2)	48.6% (17)	0% (0)	31.9% (15)	50% (15)	33.3% (1)	0% (0)	20% (1)	4.76% (1)
	Sleep disturbances	57.8% (102)	75% (6)	45% (9)	62.9% (22)	0% (0)	70.2% (33)	70% (21)	33.3% (1)	16.6% (1)	100% (5)	19% (4)
	Difficulties exercising	6.7% (12)	0% (0)	10% (2)	5.7% (2)	0% (0)	8.5% (4)	6.7% (2)	0% (0)	16.6% (1)	20% (1)	0% (0)
	Suicidal	3.4% (6)	12.5% (1)	0% (0)	2.9% (1)	0% (0)	4.25% (2)	3.3% (1)	0% (0)	0% (0)	0% (0)	4.76% (1)

Statistical analysis using Mann-Whitney U tests indicated that there were significant differences in the number of TMD-related eating and swallowing problems reported by participants presenting with either TMJ- or masticatory muscle-related TMDs (U=2767, p=0.53). A Kruskal-Wallis H test indicated that there were significant differences in the number of symptoms reported by participants presenting with different TMD issues (e.g.: DDs, MFP, or myalgia) ($\chi 2(8) = 24.49$, P = .002). However, post hoc pair-wise Mann-Whitney U tests with Bonferroni's correction demonstrated no statistically significant differences between symptomatic pairings, potentially due to the increased post hoc conservative adjustment for errors and large number of secondary pairwise comparisons completed. Finally, no significant sex differences between the number of TMD-related eating and swallowing problems reported by males and females were detected (U=2470, p=0.752).

Management of Symptoms of Eating and Swallowing Disorders

Most participants reported the use of poly-modal interventions (n=165/93%), while the minority reported use of uni-modal techniques (n=8/4%), or no intervention at all (n=5/3%). Diet modifications were the most frequently used management technique by 81% of participants (n=145), followed by pain-relief medication (n=140/79%), and oral splints (n=133/75%) (see Table 21). Over half (n=110/62%) had been advised to carry out rehabilitative exercises by the clinicians practicing within recruitment locations. A third (n=59/33%) used adapted feeding utensils, with straws being used most commonly (n=43/24%). Overall, of the interventions specifically listed in the TEDSS Management subscale, acupuncture was the least frequently used intervention (n=27/15%), with those experiencing masticatory muscle disorders using this intervention more frequently than those with TMJ-related issues.

Table 21: Investigated Management Techniques

Management Techniques		Overall Sample	Arthralgia	Myalgia	MFP	Headache attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Pain management		78.65 % (140)	87.5% (7)	85% (17)	80% (28)	66.6% (2)	76.59% (36)	57.5% (23)	100% (3)	83.3% (5)	80% (4)	71.42% (15)
Adapted feeding utensils	*Straws*	24.15% (43)	12.5% (1)	35% (7)	28.57% (10)	33.3% (1)	21.27% (10)	23.3% (7)	66.6% (2)	16.66% (1)	60% (3)	4.76% (1)
	Bottles	12.92% (23)	12.5% (1)	5% (1)	20% (7)	33.3% (1)	12.76% (6)	6.66% (2)	66.6% (2)	16.66% (1)	40% (2)	0 (0%)
	Cups	7.86% (14)	12.5% (1)	0 (0%)	17.14% (6)	33.3% (1)	6.38% (3)	3.33% (1)	0 (0%)	16.66% (1)	20% (1)	0 (0%)
	Cutlery	21.91% (39)	12.5% (1)	20% (4)	22.85% (8)	33.3% (1)	25.53% (12)	23.33% (7)	66.6% (2)	16.66% (1)	20% (1)	9.52% (2)
Oral splints		74.71 % (133)	87.5% (7)	65% (13)	68.57 % (24)	100% (3)	91.48% (43)	73.3% (22)	100% (3)	50% (3)	40% (2)	61.9% (13)
Acupuncture		15.16 % (27)	12.5% (1)	20% (4)	20% (7)	0% (0)	10.63% (5)	33.3% (10)	0% (0)	0% (0)	0% (0)	0% (0)
Exercises		61.79 % (110)	75% (6)	50% (10)	57.14 % (20)	66.6% (2)	72.34% (34)	73.33% (22)	100% (3)	33.3% (2)	60% (3)	38.09% (8)
Diet modifications		81.46 % (145)	62.5% (5)	85% (17)	85.71 % (30)	33.3% (1)	82.97% (39)	80% (24)	100% (3)	66.6% (4)	100% (5)	80.95% (17)

Participants also reported using a range of “other” intervention strategies (see Table 22). The most frequently used technique was complete avoidance of eating when symptoms were worst (n=152/85%), with trends indicating that participants with TMJ-related issues avoided eating to the greatest degree. The use of conservative measures including heat packs (n=89/50%), self-massage (n=63/35%), avoiding talking (n=45/25%), and ice packs (n=42/24%) was also reported. Surgery was used in cases of non-refractory TMDs, with arthrocentesis and eminectomy being the most commonly used methods (n=29/16% and n=14/8%, respectively). Finally, relaxation strategies (e.g.: non-specific meditation, relaxing music, and guided imagery techniques) were employed by a fifth of respondents (n=32/18%).

Table 22: Other Management Techniques

Other Management Techniques		Overall Sample	Arthralgia	Myalgia	MFP	Headache attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Thermal interventions	*Ice packs*	23.59% (42)	25% (2)	5% (1)	22.85% (8)	0% (0)	34.04% (16)	30% (9)	66.6% (2)	0% (0)	20% (1)	14.28% (3)
	Cooling gels	14.04% (25)	0% (0)	5% (1)	17.14% (6)	0% (0)	21.27% (10)	20% (6)	0% (0)	0% (0)	20% (1)	4.76% (1)
	Heat packs	50% (89)	50% (4)	25% (5)	42.85% (15)	0% (0)	63.82% (30)	73.3% (22)	66.6% (2)	16.6% (1)	80% (4)	28.57% (6)
	Heating gels	23.03% (41)	0% (0)	5% (1)	31.42% (11)	0% (0)	31.91% (15)	40% (12)	0% (0)	0% (0)	40% (2)	0% (0)
Surgical interventions	*Steroid injections*	6.17% (11)	12.5% (1)	0% (0)	5.71% (2)	0% (0)	6.38% (3)	13.3% (4)	33.3% (1)	0% (0)	0% (0)	0% (0)
	Botulinum toxin injections	4.49% (8)	0% (0)	10% (2)	11.42% (4)	0% (0)	2.12% (1)	3.33% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Arthroscopy	0.56% (1)	0% (0)	0% (0)	0% (0)	0% (0)	2.12% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
	Arthrocentesis	16.29% (29)	0% (0)	5% (1)	5.71% (2)	0% (0)	21.27% (10)	40% (12)	33.3% (1)	16.6% (1)	40% (2)	0% (0)
	Eminectomy	7.86% (14)	0% (0)	0% (0)	2.85% (1)	0% (0)	6.38% (3)	30% (9)	0% (0)	0% (0)	20% (1)	0% (0)
Dental interventions	*Tooth extractions*	1.12% (2)	0% (0)	0% (0)	2.85% (1)	0% (0)	3.33% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
	Orthodontics	1.12% (2)	0% (0)	0% (0)	2.85% (1)	0% (0)	3.33% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
Avoidance of ADLs	*Avoid eating*	85.39% (152)	87.5% (7)	100% (20)	74.28% (26)	100% (3)	89.36% (42)	86.6% (26)	100% (3)	50% (3)	100% (5)	80.95% (17)
	Avoid talking	25.28% (45)	0% (0)	0% (0)	40% (14)	0% (0)	36.17% (17)	30% (9)	0% (0)	0% (0)	40% (2)	14.28% (3)
	Avoid singing	21.92% (39)	12.5% (1)	0% (0)	31.42% (11)	0% (0)	31.91% (15)	30% (9)	0% (0)	0% (0)	40% (2)	4.76% (1)
Psychological interventions	*Cognitive behaviour therapy*	6.17% (11)	0% (0)	0% (0)	5.71% (2)	0% (0)	4.25% (2)	16.66% (5)	0% (0)	0% (0)	40% (2)	0% (0)
	Relaxation techniques (e.g.: music, meditation)	17.97% (32)	37.5% (3)	0% (0)	14.28% (5)	0% (0)	23.4% (11)	23.3% (7)	33.3% (1)	0% (0)	40% (2)	14.28% (3)
Alternative Therapies	*Craniosacral therapy*	1.12% (2)	0% (0)	0% (0)	0% (0)	0% (0)	4.25% (2)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)

	Massage	35.39% (63)	37.5% (3)	35% (7)	28.57% (10)	0% (0)	36.17% (17)	50% (15)	66.6% (2)	16.6% (1)	80% (4)	19.04% (4)
	Dry needling	1.68% (3)	0% (0)	0% (0)	2.85% (1)	0% (0)	2.12% (1)	3.33% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Homeopathy	3.37% (6)	12.5% (1)	5% (1)	5.71% (2)	0% (0)	4.25% (2)	3.33% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Chiropractor	3.37% (6)	0% (0)	0% (0)	11.42% (4)	0% (0)	2.12% (1)	3.3% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Aromatherapy	2.8% (5)	0% (0)	0% (0)	5.71% (2)	0% (0)	4.25% (2)	3.3% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Osteopathy	1.12% (2)	0% (0)	0% (0)	2.85% (1)	0% (0)	2.12% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
	Reiki	1.68% (3)	0% (0)	0% (0)	5.71% (2)	0% (0)	2.12% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
	Clove oil	0.5% (1)	0% (0)	0% (0)	2.85% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
Recreational substances	*Alcohol*	1.12% (2)	0% (0)	5% (1)	0% (0)	0% (0)	0% (0)	3.3% (1)	0% (0)	0% (0)	0% (0)	0% (0)
	Marijuana	0.5% (1)	0% (0)	0% (0)	2.85% (1)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)	0% (0)
Physiotherapy		7.3% (13)	12.5% (1)	5% (1)	5.71% (2)	0% (0)	12.76% (6)	6.6% (2)	0% (0)	0% (0)	20% (1)	0% (0)
Physical exercise		5.05% (9)	0% (0)	0% (0)	5.71% (2)	0% (0)	10.63% (5)	3.33% (1)	0% (0)	0% (0)	0% (0)	4.76% (1)

A Mann-Whitney U test indicated that there were no significant sex differences in the overall number of management techniques used by females or males (U=2178, p=0.164), or in the number of techniques used by participants presenting with masticatory muscle or TMJ disorders (U=2474.5, p=0.08). A Kruskal-Wallis H test indicated that there were statistically significant differences in overall number of management techniques used between participants presenting with different TMD issues ($\chi 2(8) = 17.8$, P = .023). However, post hoc pair-wise Mann-Whitney U tests with Bonferroni's correction indicated that there were no statistically significant differences between specific symptomatic profiles. A Spearman's rank correlation coefficient was calculated, showing a statistically significant correlation between overall number of eating and swallowing problems reported and overall number of management techniques used ($r=0.51$, $P<0.05$).

5.3. Discussion

This study found that within the recruited sample, adults presenting with TMDs commonly experienced eating and swallowing problems. In addition, a snapshot of the current management of TMD-related eating and swallowing problems within Irish specialist care centres was provided. Results suggest that management in these contexts is variable, with the use of both eating and swallowing-specific and non-specific techniques reported, and poly-modal intervention programs being commonly implemented. Therefore, this research has provided new information on a previously under-explored condition, while also documenting the range of interventions of which these patients typically avail.

As noted, eating and swallowing difficulties were reported by patients with TMDs in this sample. Epidemiological findings of this study differed to those previously reported, with regards to the higher prevalence estimates and the broader range of eating and swallowing problems reported by patients here. This lack of concordance with prior results may relate to: 1) the dedicated focus of this study on specific TMD-related eating and swallowing problems, and 2) the use of a cohort-specific structured interview tool in data collection. While TMD symptoms such as masticatory impairments were previously discussed, limited research on the oropharyngeal consequences of these issues had been conducted. Here, a third of participants experienced swallowing problems, while respondents also reported both weight loss, and indeed gain, as consequences of impaired mastication. Also, almost half of participants reported anxiety, embarrassment, and subsequent social withdrawal due to impaired eating and swallowing, therefore underlining the need for further research to investigate the functional and psychosocial impact of these problems.

Recently, research has advocated the provision of poly-modal TMD interventions which account for the multi-factorial aetiology of these conditions(235,244,266). As discussed, the concurrent use of poly-modal management techniques including a range of eating and swallowing -specific and non-specific methods were reported by most participants here (n=165/93%). However, the data gathered here did not differentiate between interventions which were recommended by clinicians working at recruitment sites, versus those which were recommended by other clinicians to which patients had presented, or those which patients had researched and implemented

independently. Patients experiencing TMDs typically demonstrate high levels of reliance on healthcare services, with reports of cross-discipline treatment-seeking in attempts to gain relief from chronic pain and dysfunction(267). It is hypothesised here that cross-discipline treatment-seeking may be elevated in patients with TMDs experiencing eating and swallowing problems, due to the potential for increased physical and psychosocial impact. Therefore, this data may inform the need to design specific remediation plans, and may influence the future construction of MDT networks which are inclusive of professionals with expertise in the management of eating and swallowing problems (e.g.: the SLT and dietitian).

Study Limitations

The main limitation of this study is that treatment-seeking patients presenting to national specialist centres of care for the management of TMDs were sampled. As such, this cohort may be represented by individuals with more severe difficulties than those attending general dental or medical practices for management or those who are self-managing their difficulties independently. Therefore, it is recommended that future studies investigate TMD-related eating and swallowing problems in diverse cohorts to ensure that results are representative.

Recommendations

While the TEDSS was adapted from existing tools which themselves have been validated, the amalgamated structured interview tool has yet to be assessed in such a manner. As such, it must be used with large, representative samples to ensure the sensitivity and specificity of the instrument. Similarly, while this study provides new data on eating and swallowing problems in adults with TMDs, subjective patient questionnaires were the sole method of data collection. It is recommended that future epidemiological research be conducted using both subjective assessment tools and IROMs to ensure valid and reliable data is gathered. Finally, the expansion of typical MDT networks to include professionals with expertise in the management of eating and swallowing problems is also advocated.

5.4. Summary and Conclusions

This study highlighted that eating and swallowing problems are experienced by treatment-seeking adults with TMDs, and has provided a snapshot of the varied management techniques employed within an Irish specialist clinical context to address these issues. In addition, avenues for future clinical developments were also suggested via development of a structured interview tool dedicated for use with this patient group.

Chapter Six: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

6.0. Introduction

Findings from Chapter 5 indicated that patients with TMDs experience masticatory impairments which can cause subsequent eating and swallowing problems. Research from other clinical groups who experience eating and swallowing problems has found that these issues impact on both physical functioning and emotional well-being by reducing the ability to consume typical diets, decreasing participation in social events, eroding self-esteem, and creating a sense of diversity compared to peers(268,269). Although little is known about the functional or psychosocial consequences of TMD-related eating and swallowing problems specifically, it is hypothesised here that the impact of these difficulties may be similarly negative.

Research suggests that providing health information that is congruent with patient needs is associated with improved HRQOL and that appropriate information provision can decrease the physical and emotional impact of a condition(270). Patients who receive information targeted to their needs report a lower frequency and severity of physical symptoms, in conjunction with reduced rates of anxiety and depression (270–272). Findings from Chapter 3 demonstrated that 97% of clinicians surveyed consider patient education on eating and swallowing problems to be an important clinical outcome for this group, although many highlighted that they currently have limited access to information on these difficulties.

Therefore, a cross-sectional prospective study was conducted here to examine the prevalence, nature, and impact of eating and swallowing problems in adults with TMDs. In addition, participant priorities regarding the provision of information on eating and swallowing problems during TMD management were also surveyed, and a pilot educational booklet was developed to support clinicians in their provision of this information to patients with TMDs.

6.1. Methods

The methods used in this study will be presented below, with a focus on eligibility criteria, data collection, and analytical measures.

Study Design

Similar to Chapter 5, a cross-sectional study design was used here to examine the prevalence, nature, and impact of eating and swallowing problems in adults with TMDs presenting consecutively to 2 national specialist centres of care over a 12 month period (see Section 5.1.). Ethical approval was granted by the SJH/TUH Research Ethics Committee to conduct this study (see Appendix 14).

Research Settings

The sampling frames and research settings selected for use here were the patient lists for Oral Surgery and OMFS outpatient clinics in the DDUH and the NMU, SJH (see Section 5.1.).

Participants

Participants were eligible for inclusion if they were adult patients (aged 18 years and older) of any sex, race, or TMD severity level seeking treatment from Oral Surgery and OMFS clinics in the DDUH, or the NMU, as assessed using the DC/TMD(15) or RDC/TMD classification systems(148). Individuals were excluded if they were aged below 18 years or if they presented with a history of relevant comorbid conditions affecting mandibular functioning (e.g.: facial trauma, head and neck cancer, neurological pathology, or congenital orofacial conditions)(262,263). Individuals were also excluded if they presented with coeliac disease as participation involved mastication of a cracker containing gluten. As it was unknown the number of eligible participants presenting to sampling locations over a 12-month period, it was not possible to prospectively calculate sample size.

Materials Used

After participants read the PIL (see Appendix 15) and signed the informed consent form (see Appendix 16), a new assessment protocol was used to gather data on: stomatognathic functioning, eating and swallowing status, and levels of activity, participation, and pain-related disability. Instruments in this protocol were stratified as per assessments which the participant completed independently and those which were administered by the researcher (see Table 23).

Table 23: Instrumentation used in Data Collection

Instrument Name	Purpose of Instrument
Measures completed by Participant	
Axis I of the DC/TMD: DC/TMD Symptom Questionnaire(15) (see Appendix 17)	To assess physiological facets of TMD pain and dysfunction (e.g.: the presence, frequency, intensity, and source of TMJ pain, perceptual jaw noises, open and closed jaw locking, the presence and nature of headaches, and functional pain modification)
Axis II of the DC/TMD: The JFLS-8(264) (see Appendix 18)	To assess global limitations in mastication and jaw mobility in functional activities
Axis II of the DC/TMD: The GCPS(273) (see Appendix 19)	To assess patient-reported global pain severity, pain-intensity, and pain-related disability
Axis II of the DC/TMD: The PHQ-4(274) (see Appendix 20)	To assess psychological distress and difficulties in emotional functioning attributed to anxiety and/or depression
Axis II of the DC/TMD: The OBC(275) (see Appendix 21)	To assess the frequency of maladaptive oral parafunctional behaviours which may cause repetitive stomatognathic microtrauma contributing to both the development of TMDs and the perpetuation of their chronicity
The Dysphagia Handicap Index (DHI)(276) (see Appendix 22)	To assess the perceived emotional, functional, and physical impact of eating and swallowing problems on activity and participation in ADLs
Measures completed by Researcher	
Axis I of the DC/TMD: The DC/TMD Examination Tool(15) (see Appendix 23)	To assess the location, modification, and nature of dysfunction within the TMJ, muscles of mastication, and associated structures
Orofacial Examination Tool(277) (see Appendix 24)	To assess the sensory and motor functioning of the lips, tongue, jaw, soft palate, and aerodigestive tract to ensure that participants do not present with concomitant difficulties
The TOMASS(226) (see Appendix 25)	To assess the oral preparatory phase of swallowing and reduced solid food swallowing efficiency

In addition to the investigation of eating and swallowing status, data was also gathered on the health information needs of participants. This data was gathered to determine patient priorities on

the provision of information about eating and swallowing during TMD management and to ultimately facilitate the development of a patient education tool. A paper-based survey was used here which was designed following review of literature on patient priorities about the provision of disease-related information, and the development of educational tools (see Appendix 26). This resulted in the derivation of 3 key themes:

1. The degree and sufficiency of information participants received about their presenting complaints;
2. The information which participants would like to receive regarding:
    a. Epidemiology of TMD-related eating and swallowing problems;
    b. Methods of management,
    c. Useful resources with further information.
3. The optimal format and timing of information provision.

Survey completion involved respondents answering 6 questions about information which they had received on their eating and swallowing problems, what information they still require, and whether an educational booklet providing this information would be beneficial. Participants also indicated which information on TMD-related eating and swallowing problems they perceived to be "important", "somewhat important", or "not important".

All participants were also provided with a draft information booklet on the epidemiology, nature impact, and management of TMD-related eating and swallowing problems (see Appendix 27). Information included in the booklet was derived from the investigation of the epidemiology and nature of eating and swallowing problems in adults with TMDs (see Sections 4.2. and 5.2.) and the examination of typical management techniques used in this field (see Sections 3.2. and 5.2.). Formatting of the booklet was conducted in-line with available guidelines for the development of patient educational tools (278,279). Participant feedback was used to assess if this booklet adequately satisfied patients' information needs, and this feedback will guide future tool refinement. Subsequent to manuscript submission, the final version will be disseminated at the sampling locations in order to support patient education.

Data Collection

Consecutive adult patients with TMDs self-selected to participate in this study on their presentation to the research locations over a 12-month period (March 2017–March 2018). Information posters (see Appendix 28) were present in each clinical site outlining eligibility criteria and procedures involved in participation. Information was also provided on these posters regarding self-selection processes. In order to self-select, the participant indicated interest to the clinic secretary who then alerted the researcher. The researcher subsequently provided respondents with further information via provision of a PIL (see Appendix 15). If interested in participation, the individual then signed an informed consent form (see Appendix 16), was assessed for eligibility, and completed assessment protocols following a reflective period.

Statistical Analysis

Descriptive statistics were reported for all demographic data. In addition, statistical analysis was conducted using both parametric and non-parametric tests. Chi-squared tests were performed at the 5% significance level to determine associations between categorical variables. T-tests, Mann-Whitney U, Kruskal-Wallis, and Spearman's rho nonparametric correlation tests were also used to identify significant differences between the distributions of groups, and to identify associations between continuous variables. Statistical analysis was conducted in conjunction with the Centre for Support and Training in Analysis and Research, University College Dublin.

6.2. Results

Over the 12-month period, 128 individuals were approached, with 126 ultimately participating, yielding a 98.4% response rate.

Respondent Demographics

Respondent characteristics are described in Table 24. The mean age of the sample was 40.32 years (SD: 16.01 / range: 18-78), with a female: male representation ratio of 5.3:1. Overall, TMJ disorders were most commonly experienced (right: n=8/64.28% / left: n=83/65.83%). With reference to specific profiles, DDWOR with limited opening (DDWORWLO) was the most common TMJ disorder, regardless of TMJ side. MFP with referral (MFPWR) was the most frequent masticatory muscle disorder. The mean time since the onset of eating and swallowing problems was 60 months/5 years (SD: 60.9/ range: 2-360 months), with females and males reporting similar mean time since onset (60 months and 58 months, respectively).

Table 24: Demographics of Study Sample by Symptom Categories

		Age		Gender - male	Gender - female
	N	**mean (SD)**	**median (range)**	**n (%)**	**n (%)**
Overall	126	40.32 (16.01)	36 (18-78)	20 (15.9)	106 (84.1)
Overall Symptom Categories – Right					
None	27	44.59 (16.55)	45 (18-78)	6 (22.2)	21 (77.8)
Masticatory Muscle Disorders	18	45.11 (16.94)	43 (18-77)	4 (22.2)	14 (77.8)
TMJ Disorders	81	37.83 (15.27)	34 (18-77)	10 (12.3)	71 (87.7)
Specific Symptom Categories – Right					
None	26	44.38 (16.84)	45 (18-78)	6 (23.1)	20 (76.9)
Myalgia	2	61.00 (22.63)	61 (45-77)	0 (0)	2 (100.0)
MFPWR	13	44.08 (15.36)	42 (18-68)	4 (30.8)	9 (69.2)
Arthralgia	1	77.00 (-)	77 (-)	0 (0)	1 (100.0)
DDWR	12	31.25 (13.13)	28.5 (18-60)	2 (16.7)	10 (83.3)
DDWRIL	17	39.29 (15.60)	34 (22-75)	2 (11.8)	15 (88.2)
DDWORWLO	47	36.64 (14.44)	34 (18-71)	4 (8.5)	43 (91.5)
DDWORWOLO	1	55.00 (-)	55 (-)	0 (0)	1 (100.0)
Dislocation	5	48.40 (17.07)	46 (32-67)	2 (40.0)	3 (60.0)
RA	2	46.00 (2.83)	46 (44-48)	0 (0)	2 (100.0)
Overall Symptom Categories – Left					
None	26	39.12 (16.65)	34 (18-75)	4 (15.4)	22 (84.6)
Masticatory Muscle Disorders	17	45.00 (17.72)	42 (18-77)	7 (41.2)	10 (58.8)
TMJ Disorders	83	39.73 (15.48)	36 (18-78)	9 (10.8)	74 (89.2)
Specific Symptom Categories – Left					
None	27	38.56 (15.97)	34 (18-75)	4 (14.8)	23 (85.2)
Myalgia	2	61.00 (22.63)	61 (45-77)	0 (0)	2 (100.0)
MFPWR	14	42.79 (17.39)	39.5 (18-73)	7 (50.0)	7 (50.0)
Arthralgia	1	77.00 (-)	77 (-)	0 (0)	1 (100.0)
DDWR	10	42.10 (19.96)	41.5 (18-73)	2 (20.0)	8 (80.0)
DDWRIL	17	45.29 (13.52)	48 (24-65)	1 (5.9)	16 (94.1)
DDWORWLO	46	36.04 (12.69)	32.5 (18-59)	4 (8.7)	42 (91.3)
DDWORWOLO	3	33.00 (19.47)	26 (18-55)	1 (33.3)	2 (66.6)
Dislocation	4	41.75 (19.50)	39 (22-67)	1 (25.0)	3 (75.0)
RA	2	63.00 (21.21)	63.00 (48-78)	0 (0)	2 (100.0)

**DDWRIL- disc displacement with reduction with intermittent locking; DDWORWOLO- disc displacement without reduction without limited opening*

Subjective Mastication, Eating, and Swallowing Problems

A range of subjective mastication, eating, and swallowing problems were reported by adults with TMDs, and relevent data on these issues will now be presented below.

Subjective Pain Experiences

Pain experiences varied, with most respondents experiencing constant pain since TMD onset, (n=62/49.6%), 43.2% (n=54) having fluctuating discomfort, and only 7.2% (n=9) of participants

reporting no pain (see Table 25). Most participants reported pain modification on chewing (n=110/ 87.3%). Generalised orofacial pain and headache were also prevalent (n=77/ 61.1%).

Table 25: Pain and Headache Duration and Modification

Variable	Valid N	N (%)
Pain description	125	
No pain		9 (7.2)
Comes and goes		54 (43.2)
Always present		62 (49.6)
Changed pain…		
Due to chewing	126	110 (87.3)
Due to opening mouth	126	106 (84.1)
Due to parafunctional habits	126	109 (86.5)
Due to talking	125	105 (84.0)
Headache in last 30 days	126	77 (61.1)
Headache changed…		
Due to chewing	126	58 (46.0)
Due to opening mouth	126	57 (45.2)
Due to habits	126	61 (48.4)
Due to talking	126	59 (46.8)

Most participants experienced pain at least once a day for the last 6 months (n=81/ 64.3%), with a median rating of moderate pain (6.5/10) (see Table 26).

Table 26: Descriptive Statistics of the GCPS - Pain Ratings

	Frequency of Scores - n (%)											
Variable	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Score 10**	**Median (range)**
Pain rating at time of assessment	17 (13.5)	8 (6.3)	13 (10.3)	12 (9.5)	13 (10.3)	12 (9.5)	12 (9.5)	4 (3.2)	19 (15.1)	2 (1.6)	14 (11.1)	4.5 (0 - 10)
Worst average pain rating	6 (4.8)	2 (1.6)	4 (3.2)	5 (4.0)	10 (7.9)	9 (7.1)	6 (4.8)	6 (4.8)	17 (13.5)	6 (4.8)	55 (43.7)	8 (0 - 10)
Average pain rating	7 (5.6)	5 (4.0)	9 (7.1)	11 (8.7)	9 (7.1)	12 (9.5)	10 (7.9)	3 (2.4)	14 (11.1)	3 (2.4)	43 (34.1)	6.5 (0 - 10)

The most commonly reported pain locations were the TMJ (right: n=66/ left: n=62), masseter (right: n=61/ left: n=51), and temporalis (right: n=56/ left: n=52). Almost half of all participants experienced pain in more than 1 orofacial location within the last 30 days (right: n=61/48.4% / left: n=53/42.06%).

<u>Parafunctional Habits potentially associated with the Development and Perpetuation of Eating and Swallowing Problems</u>

Parafunctional habits which may contribute to the overall presence, severity, and impact of TMD-related eating and swallowing problems were identified via analysis of OBC responses. Participants most commonly reported sleeping in a position which puts additional pressure on the TMJ on between 4-7 nights a week (n=80/ 63.5), followed by night-time bruxism (n=76/ 60.3%), and sustained talking throughout the day (n=64/ 50.8%) (see Table 27). Unilateral mastication was reported by 79% of all respondents, although it is unclear if this is a causative factor in the development of TMD-related eating and swallowing problems, or if it is a symptom of this condition.

Table 27: Descriptive Statistics of the OBC

	Frequency of Scores - n (%)					
Variable	**Never**	**<1 night/month**	**1-3 nights/month**	**1-3 nights/week**	**4-7 nights/week**	**Median (range)**
Tooth grinding/clenching in sleep	29 (22.2)	8 (6.3)	6 (4.8)	8 (6.3)	76 (60.3)	4 (0 - 4)
Sleep position that puts pressure on jaw	26 (20.6)	6 (4.8)	5 (4.0)	9 (7.1)	80 (63.5)	4 (0 - 4)
Tooth grinding while awake	46 (36.5)	15 (11.9)	12 (9.5)	4 (3.2)	49 (38.9)	2 (0 - 4)
Tooth clenching while awake	34 (27.0)	15 (11.9)	14 (11.1)	12 (9.5)	50 (39.7)	2.5 (0 - 4)
Tooth contact when not eating	35 (27.8)	12 (9.5)	13 (10.3)	10 (7.9)	56 (44.4)	3 (0 - 4)
Jaw tension without clenching/contact	36 (28.6)	14 (11.1)	14 (11.1)	10 (7.9)	52 (41.3)	2 (0 - 4)
Jaw jutting	46 (36.5)	10 (7.9)	9 (7.1)	7 (5.6)	54 (42.9)	2 (0 - 4)
Tongue thrust	48 (38.1)	14 (11.1)	10 (7.9)	6 (4.8)	48 (38.1)	2 (0 - 4)
Tongue between teeth	49 (38.9)	14 (11.1)	12 (9.5)	5 (4.0)	46 (36.5)	1.5 (0 - 4)
Bite/chew/play with cheeks/tongue/lips	44 (34.9)	13 (10.3)	9 (7.1)	9 (7.1)	51 (40.5)	2 (0 - 4)
Jaw bracing	51 (40.5)	10 (7.9)	11 (8.7)	7 (5.6)	47 (37.3)	2 (0 - 4)
Hold things between teeth	66 (52.4)	12 (9.5)	3 (2.4)	4 (3.2)	41 (32.5)	0 (0 - 4)
Chewing gum	69 (54.8)	18 (14.3)	5 (4.0)	6 (4.8)	28 (22.2)	0 (0 - 4)
Play musical instrument that uses mouth/jaw	84 (66.7)	10 (7.9)	4 (3.2)	1 (0.8)	27 (21.4)	0 (0 - 4)
Lean jaw on hand	43 (34.1)	14 (11.1)	10 (7.9)	14 (11.1)	45 (35.7)	2 (0 - 4)
Unilateral mastication	26 (20.6)	15 (11.9)	11 (8.7)	20 (15.9)	54 (42.9)	3 (0 - 4)
Eating between meals	36 (28.6)	18 (14.3)	12 (9.5)	12 (9.5)	48 (38.1)	2 (0 - 4)
Sustained talking	32 (25.4)	16 (12.7)	7 (5.6)	7 (5.6)	64 (50.8)	4 (0 - 4)
Singing	53 (42.1)	14 (11.1)	8 (6.3)	8 (6.3)	43 (34.1)	1 (0 - 4)
Yawning	23 (18.3)	17 (13.5)	13 (10.3)	13 (10.3)	60 (47.6)	3 (0 - 4)
Hold telephone between head and shoulders	64 (50.8)	11 (8.7)	10 (7.9)	5 (4.0)	36 (28.6)	0 (0 - 4)

A highly significant negative correlation was found between the frequency of sustained talking and age (rho = -0.314, $p < 0.001$), which suggests that younger patients talk at length more frequently than older patients. In addition, female patients were significantly more likely than males to hold the telephone between their head and shoulders 4-7 times a week (chi-squared = 14.33, P = 0.006). No significant differences between any OBC criteria were found as per overall/specific symptom categories.

Subjective Impairments of Mastication, Eating, and Swallowing

Using the JFLS, a range of masticatory, eating, and swallowing impairments were reported, with the majority of participants experiencing the most severe difficulties chewing tough food (n=65/ 51.6%), while a quarter experienced the most severe difficulties chewing chicken (n=33/ 26.2%),

swallowing (n=32/ 25.4%), and opening their mouth wide enough to adequately drink from a cup (n=29/ 23%) (see Table 28).

Table 28: Descriptive Statistics of the JFLS

	Frequency of Scores - n (%)											
Variable	**Score 0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Score 10**	**Median (range)**
Chew tough food	6 (4.8)	2 (2.4)	3 (2.4)	1 (7.9)	3 (2.4)	9 (7.1)	5 (4.0)	7 (5.6)	9 (7.1)	6 (4.8)	65 (51.6)	10 (0 - 10)
Chew chicken	25 (19.8)	2 (2.4)	13 (10.3)	9 (7.1)	6 (4.8)	15 (11.9)	8 (6.3)	5 (4.0)	8 (6.3)	1 (0.8)	33 (26.2)	5 (0 - 10)
Chew soft food	60 (47.6)	3 (2.4)	9 (7.1)	11 (8.7)	5 (4.0)	4 (3.2)	4 (3.2)	2 (1.6)	4 (3.2)	0 (0)	24 (19.0)	1.5 (0 - 10)
Drink from cup	58 (46.0)	2 (1.6)	2 (1.6)	6 (4.8)	3 (2.4)	13 (10.3)	4 (3.2)	3 (2.4)	5 (4.0)	1 (0.8)	29 (23.0)	3 (0 - 10)
Swallow	59 (46.8)	2 (1.6)	7 (5.6)	7 (5.6)	2 (1.6)	6 (4.8)	3 (2.4)	2 (1.6)	4 (3.2)	2 (1.6)	32 (25.4)	2 (0 - 10)
Yawn	15 (11.9)	2 (1.6)	3 (2.4)	9 (7.1)	6 (4.8)	7 (5.6)	6 (4.8)	5 (4.0)	9 (7.1)	7 (5.6)	57 (45.2)	9 (0 - 10)
Talk	39 (31.0)	3 (2.4)	6 (4.8)	5 (4.0)	3 (2.4)	12 (9.5)	4 (3.2)	6 (4.8)	5 (4.0)	2 (1.6)	41 (32.5)	5 (0 - 10)
Smile	44 (34.9)	3 (2.4)	8 (6.3)	3 (2.4)	4 (3.2)	10 (7.9)	3 (2.4)	4 (3.2)	5 (4.0)	1 (0.8)	41 (32.5)	5 (0 - 10)

Individuals with overall right-sided TMJ disorders were significantly more likely to report greater difficulties chewing tough food than those with a right-sided masticatory muscle disorder or no right-sided symptoms (Kruskal-Wallis chi-squared = 10.04, P = 0.007), while individuals with right-sided DDWORLO reported significantly greater difficulties chewing tough food than other symptom profiles, and those with myalgia reporting the least severe difficulties in this area (Kruskal-Wallis chi-squared = 16.79, P = 0.032). No significant differences were found regarding left-sided, overall, or specific symptom profiles. In addition, no significant differences were found between different genders or age groups regarding difficulties: chewing tough food, chicken, or soft food, opening wide enough to drink from a cup, or swallowing.

Using the DHI tool, the composite severity of eating and swallowing problems caused by impaired mastication were rated on a scale of 0-7, with 7 being the most severe rating. Almost half of the 126 respondents rated their eating and swallowing problems as the most severe rating (7) (n=55/ 43.7%), followed by 15.1% (n=19) and 14.3% (n=18) who had respective moderate scores of 4 and 5, and 15 (11.9%) with a mild score of 1. The median overall severity score was 5.5 (moderate severity). There was a significant difference in the composite severity score regarding overall right-sided TMJ symptom profiles (chi-squared = 30.81, P = 0.006). Of the 27 patients with no right-sided symptoms, 10 (37%) reported the highest and most severe score of 7, while 7 (26%) reported a score of 4, and 7 (26%) reported a score of 5. Of the 18 patients with right-sided masticatory muscle disorders, 6 (33%) reported a score of 7, and 7 (39%) reported a score of 1. Of the 81 patients with right-sided TMJ disorders, 39 (48%) reported a score of 7, followed by 10 (12%) reporting a score of 5.

The most commonly reported eating and swallowing difficulties were the need to clear oral residue via liquid washdowns (n=86/ 68.3%) and multiple swallows (n=73/ 57.9%) (see Table 29). In addition, 50% (n=63) of participants reported weight loss, while 46.5% (n=60) experienced a

strangling sensation while swallowing, 45.2% (n=57) had previously choked on medications, and 40.5% (n=51) had to cough up solid boluses after swallowing due to oropharyngeal transit issues.

Table 29: Descriptive Statistics of the DHI - Physical Subscale

		Frequency of Scores - n (%)			
	Variable	**Never**	**Sometimes**	**Always**	**Median (range)**
Physical	Coughing on drinking	80 (63.5)	33 (26.2)	13 (10.3)	0 (0 - 2)
	Coughing on eating	87 (69.0)	28 (22.2)	11 (8.7)	0 (0 - 2)
	Dry mouth	52 (41.3)	47 (37.3)	27 (21.4)	1 (0 - 2)
	Need to drink to wash food down	40 (31.7)	48 (38.1)	38 (30.2)	1 (0 - 2)
	Lost weight	63 (50.0)	33 (26.2)	30 (23.8)	0.5 (0 - 2)
	Must swallow again before food will go down	53 (42.1)	33 (26.2)	40 (31.7)	1 (0 - 2)
	Choking on medication	69 (54.8)	27 (21.4)	30 (23.8)	0 (0 - 2)
	Strangling sensation on swallowing	66 (52.4)	28 (22.2)	32 (25.4)	0 (0 - 2)
	Coughing up food after swallow	75 (59.5)	25 (19.8)	26 (20.6)	0 (0 - 2)

There was a significant difference regarding “choking on medications” by the specific left-sided symptoms (chi-square 32.05, P = 0.022). Of the 27 patients with no specific left symptoms, 17 (63%) report never choking on medication. Of the 14 patients with MFPWR, 10 (71%) reported never choking on medication. Of the 10 participants with DDWR, 8 (80%) reported never choking on medication. Of the 17 patients with DDWRIL, 10 (59%) reported never choking and 5 (29%) reported always choking on medication. Of the 46 DDWORWLO patients, 20 (43%) reported never choking, while 15 (33%) reported always choking.

Investigator Reported Outcome Measures of Mastication, Eating, and Swallowing Problems

A range of investigator reported findings on participants’ orofacial status, mastication, eating, and swallowing skills were generated here, as will be presented below.

Orofacial Status at Rest

Most participants had adequate functional units to facilitate mastication (n=114/ 90.5%) (see Table 30).

Table 30: Descriptive Statistics for Oral Status

	Variable	**n (%)**
Oral Status	Within normal limits	114 (90.5)
	Decay	15 (11.9)
	Missing teeth	18 (14.28)
	Dentures	2 (1.6)

The orofacial parameters of most participants at rest were within normal limits (see Table 31).

Table 31: Descriptive Statistics of Orofacial Exam – At Rest

At rest	Within normal limits (n (%))	Edema	Lesion	Erythema
Lips	125 (99.2)	1 (0.8)	0 (0)	0 (0)
Tongue	125 (99.2)	1 (0.8)	0 (0)	0 (0)
Jaw	120 (95.2)	3 (2.4)	2 (1.6)	1 (0.8)
Soft Palate	125 (99.2)	1 (0.8)	0 (0)	0 (0)

Orofacial Movement within Discrete Tasks

The majority of participants demonstrated lip, tongue, and soft palate movements which were within normal limits (see Table 32).

Table 32: Descriptive Statistics of Orofacial Movements

	Variable	Within normal limits (n (%))	Mild	Moderate	Severe
Lips	Symmetry	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	ROM	124 (98.4)	1 (0.8)	1 (0.8)	0 (0.0)
	Speed	124 (98.4)	1 (0.8)	1 (0.8)	0 (0.0)
	Strength	124 (98.4)	1 (0.8)	1 (0.8)	0 (0.0)
	Tone	124 (98.4)	1 (0.8)	1 (0.8)	0 (0.0)
	Pucker	123 (97.6)	2 (1.6)	1 (0.8)	0 (0.0)
	Retraction	123 (97.6)	2 (1.6)	1 (0.8)	0 (0.0)
	Alternative pucker/retraction	123 (97.6)	2 (1.6)	1 (0.8)	0 (0.0)
Tongue	Symmetry	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	ROM	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Speed	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Strength	125 (99.2)	0	0 (0.0)	0 (0.0)
	Tone	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Protrusion	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Retraction	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Lateralisation	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
Soft Palate	Symmetry	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	ROM	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Speed	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Strength	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Tone	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Elevation	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Sustained elevation	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)
	Alternative elevate/relax	125 (99.2)	1 (0.8)	0 (0.0)	0 (0.0)

However, findings regarding TMJ parameters were varied (see Table 33). TMJ symmetry, strength, and tone were within normal limits across most participants. Yet, TMJ ROM, specifically

opening, protrusion, retraction, and lateralisation, were severely disordered in up to a fifth of participants. There was a significant difference in responses for the “TMJ ROM” parameter by gender (chi-squared = 10.387, P = 0.016). Fourteen (70%) of the 20 men had a ROM within normal limits, whereas the women were more spread out across the categories. Of the 106 women, 34 (32%) were within normal limits, 31 (29%) were categorised as mild, 22 (21%) as moderate, and 19 (18%) as severe. However, no significant differences based on overall/specific symptoms across orofacial examination parameters were detected.

Table 33: Descriptive Statistics of Jaw Movements

	Variable	Within normal limits (n (%))	Mild	Moderate	Severe
TMJ	Symmetry	115 (91.3)	7 (5.6)	3 (2.4)	1 (0.8)
	ROM	48 (38.1)	33 (26.2)	24 (19.0)	21 (16.7)
	Speed	88 (69.8)	17 (13.5)	5 (4.0)	16 (12.7)
	Strength	112 (88.9)	8 (6.3)	3 (2.4)	3 (2.4)
	Tone	112 (88.9)	8 (6.3)	3 (2.4)	3 (2.4)
	Protrusion	49 (38.9)	30 (23.8)	23 (18.3)	24 (19.0)
	Retraction	52 (41.3)	31 (24.6)	19 (15.1)	24 (19.0)
	Lateralisation	50 (39.7)	34 (27.0)	18 (14.3)	24 (19.0)
	Opening	47 (37.3)	30 (23.8)	27 (21.4)	22 (17.5)
	Closing	67 (53.2)	22 (17.5)	17 (13.5)	20 (15.9)

A range of investigator reported findings on TMJ ROM were also documented using the DC/TMD:

- The mean pain free mouth opening was 26.9 mm (SD: 9.9mm / range: 0-50 mm), which is below normal values. Those with TMJ disorders, regardless of unilateral side, showed the average lowest pain free mouth opening measurements (right: mean= 25.23mm, range= 2-45mm / left: mean= 25.9mm, range= 2-45mm).
- The mean overall maximal unassisted mouth opening was 33.89 mm (SD: 11.58 mm / range: 0-60 mm). Participants with TMJ disorders, regardless of TMJ side, reported the lowest values (right: mean= 33.02mm, range= 3-57mm / left: mean= 33.02mm, range= 3-57mm), while those with masticatory muscle disorders reported the highest levels of maximal mouth opening (right: mean= 39.47mm, range= 0-60mm / left: mean= 39.4mm, range= 0-60mm).
- The average left lateral movement was 4.84 mm (SD: 3.5 mm / range: 0-15mm), with those with TMJ disorders reporting the lowest values (right: mean= 4.52mm, range= 0-15mm / left: mean= 4.8mm, range= 0-12mm) across both right and left TMJs, and those with only unilateral symptoms reporting the highest values (right: mean= 5.7mm, range= 0-10mm / left: mean= 4.96mm, range= 0-15mm).
- The average right lateral movement was 4.74mm (SD: 3.62 mm / range: 0-12mm), with participants with masticatory muscle disorders reporting the lowest ROM (right: mean= 4mm, range= 0-12mm / left: mean= 4.29mm, range= 0-12mm), while those with no right

symptoms (mean= 5.29mm, range= 0-12mm) and left TMJ symptoms (mean= 4.96mm, range= 0-12mm) reporting the highest ROM.

- The average protrusive movement was 2.11mm (SD: 1.95mm / range: 0-11mm), with those with TMJ disorders reporting the lowest ROM (right: mean= 2.03mm, range= 0-11mm / left: mean= 1.97mm, range= 0-11mm), and those with masticatory muscle disorders reporting the highest ROM (right: mean= 2.5mm, range= 0-10mm / left: mean= 2.58mm, range= 0-10mm).

Finally, jaw joint noises were prevalent across symptom profiles, with 42.2% of all participants (n=52) experiencing these issues. Patients with DDWORWLO were significantly more likely to report bilateral noises than other symptom profiles (right TMJ: chi-squared = 95.66, $p < 0.001$ / left TMJ: chi-squared = 134.43, $p < 0.001$). Reflecting the high representation of TMJ disorders in this sample, 38% (n=48) of all participants reported jaw locking on one or more occasion, with 32.5% (n=41) reporting their jaw being currently locked. Differences between overall symptom profiles were found, with trends suggesting that participants with masticatory muscle disorders report significantly less incidences of jaw locking than those with TMJ disorders (right TMJ: chi-squared = 63.46, $p < 0.001$ / left TMJ: chi-squared = 109.90, $p < 0.001$). Patients with DDWORLO were significantly more likely to experience jaw locking than those with other symptom profiles (right TMJ: chi-squared = 102.82, $p < 0.001$ / left TMJ: chi-squared = 147.47, $p < 0.001$). In addition, significant gender differences were found between the presence and lateralisation of reported joint locking (chi-squared = 13.23, P = 0.021), with the majority of males reporting no experience of jaw locking (n=9/ 45%) or bilateral jaw locking (n=5/ 25%), while females were more likely to experience either unilateral (n=47/ 45%) or bilateral joint locking (n=32/ 30%), rather than no locking at all. Significant differences in the incidence of current locking between those experiencing masticatory muscle and TMJ disorders were found (right TMJ: chi-squared=43.37, P<0.001 / left TMJ: chi-squared=63.42, P<0.001). Interestingly, closed locking was significantly more common than open locking (n=48/ 38% and n=23/18.25%, respectively). In addition, significantly more males than females did not experience closed locking (chi-squared = 13.25, P = 0.021).

In summary, participants here demonstrated reduced ROM and jaw locking, both of which may cause difficulties in acceptance, mastication, and formation of a solid bolus, with the potential for the development of subsequent eating and swallowing difficulties.

Investigator Reported Parameters of Mastication, Eating, and Swallowing within Functional Tasks

Only 51 of a total 126 individuals (40%) completed the TOMASS, due to the high levels of reported masticatory impairments, pain, fatigue, and modified diet consumption among these patients (see Table 34). When these findings are compared to normative TOMASS data(226) for patients aged 40-60 years (mean age in the current study: 40.32), results are incongruent. For example: mean masticatory cycles per bite reported here (15.78) were higher than the published normative values (males: 11.69-14.09/ females: 9.41-13.23) (226). In addition, the mean swallows per bite (2.08) were higher than previous normative results (males: .44-1.14/ females: .46-.89) (226). Mean time

per swallow was lower here (8.36) than normative values (males: 13.33-27.75/ females: 13.93-24.28). While the mean time per masticatory cycles here (1.43) was higher than previously reported female results (.81-1.10), this figure fell within the 95% CI of normative male results (.82-10.2) *(226)*. No significant age, gender, or symptomatic differences were found between the 5 composite TOMASS variables described in Table 34.

Table 34: Descriptive Statistics for the TOMASS

Variable	N	Mean (SD)	Median (range)
Masticatory cycles per bite	51	15.78 (7.70)	14.7 (8.4-50.0)
Masticatory cycles per swallow	51	8.83 (3.49)	8.4 (2.7-21.3)
Swallows per bite	51	2.08 (1.17)	1.8 (1.0-6.0)
Time per masticatory cycle	51	1.43 (2.60)	0.9 (0.6-17.0)
Time per swallow	51	8.36 (3.90)	7.9 (3.3-22.8)

The Impact of TMD-related Eating and Swallowing Problems

TMD-related eating and swallowing problems were found to impact on participants' functional activity, participation, and psychosocial well-being, as will now be described.

Functional Impact

Participants with TMDs reported that pain associated with mastication, eating, and swallowing interferes with daily activities (e.g.: work, school, or housework) on a median of 7 out of the previous 30 days (see Table 35). These issues were reported to have a median moderate impact on the completion of daily activities (4). The median impact on recreational, social, and family activities in the last 30 days was also moderate (4), while there was a mild median interference with occupational activities (3), with no significant differences found between gender, age, or overall or specific symptom profiles.

Table 35: Descriptive Statistics of the GCPS – Impact Ratings

	Frequency of Scores - n (%)											
Variable	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Score 10**	**Median (range)**
Average interference with daily activities	46 (36.5)	4 (3.2)	6 (4.8)	4 (3.2)	11 (8.7)	8 (6.3)	2 (1.6)	7 (5.6)	0 (0)	3 (2.4)	35 (27.8)	4 (0 - 10)
Average interference with recreational, social, and family activities	44 (34.9)	5 (4.0)	3 (2.4)	7 (5.6)	7 (5.6)	12 (9.5)	3 (2.4)	7 (5.6)	1 (0.8)	2 (1.6)	35 (27.8)	4 (0 - 10)
Average interference with work activities	50 (39.7)	3 (2.4)	6 (4.8)	5 (4.0)	4 (3.2)	11 (8.7)	2 (1.6)	6 (4.8)	3 (2.4)	1 (0.8)	35 (27.8)	3 (0 - 10)

The most common functional impact of TMD-related eating and swallowing problems included: 1) meals taking longer to eat (n=91/ 72.2%); 2) avoidance of certain foods (n= 89/ 70.6%); and 3) participants changing their typical manner of swallowing (n=85/ 67.5%) (see Table 36). In

addition, participants reported behaviours which may introduce the risk of unintentional weight changes, including: 1) changing their diet (n=80 / 63.5%); 2) eating smaller meals (n=75 / 60.3%); 3) eating less (n=68 / 54%); and 4) avoiding eating (n=65 / 51.6%). There was a significant gender difference regarding the parameter of eating smaller meals (chi-squared = 9.36, P = 0.009). Whereas most men (n=14 / 70%) never had smaller meals, the 106 females were equally split between 'never', 'sometimes' and 'always' having smaller meals. In addition, there was a significant gender difference in responses for changing their diet due to TMD-related eating and swallowing problems (chi-squared = 8.35, P = 0.015). Again, whereas most men (n=12 / 65%) reported never changing their diet, the 106 females were equally split about dietary changes.

Table 36: Descriptive Statistics of the DHI - Functional Subscale

		Frequency of Scores - n (%)			
	Variable	**Never**	**Sometimes**	**Always**	**Median (range)**
Functional	Avoiding certain foods	37 (29.4)	38 (30.2)	51 (40.5)	1 (0 - 2)
	Changing typical swallowing	41 (32.5)	37 (29.4)	48 (38.1)	1 (0 - 2)
	Meals taking longer to eat	35 (27.8)	38 (30.2)	53 (42.1)	1 (0 - 2)
	Eating smaller meals	50 (39.7)	35 (27.8)	41 (32.5)	1 (0 - 2)
	Don't socialise as much as used to	63 (50.0)	27 (21.4)	36 (28.6)	0.5 (0 - 2)
	Avoiding eating	61 (48.4)	30 (23.8)	35 (27.8)	1 (0 - 2)
	Eating less	58 (46.0)	34 (27.0)	34 (27.0)	1 (0 - 2)
	Eating in another way	78 (61.9)	25 (19.8)	23 (18.3)	0 (0 - 2)
	Changed diet	46 (36.5)	37 (29.4)	43 (34.1)	1 (0 - 2)

With regards to overall symptom profiles, there was a significant difference in responses for "taking longer to eat" by overall right-sided symptoms (chi-squared = 11.64, P = 0.020). Whereas participants with no right-sided symptoms or right masticatory muscle disorders reported never taking longer to eat most often (41% and 50%, respectively), participants with TMJ disorders most often reported always taking longer to eat (49%). There was also a significant difference in responses for changing one's diet by overall right-sided symptoms (chi-squared = 11.61, P = 0.021). Of the 27 participants that had no right-sided symptoms, 16 reported never changing their diet. Of the 18 with right–sided masticatory muscle disorders, half reported never changing their diet while half reported either sometimes or always changing their diet. Finally, of the 81 participants with right-sided TMJ disorders, 33 (41%) reported always changing their diet while 27 (33%) reported sometimes changing their diet.

Psychosocial Well-being

TMD-related eating and swallowing problems were found to cause psychosocial distress (see Table 37). Scores were distributed evenly across the 4 levels of PHQ-4 distress intensity, with a tendency toward less frequent experiences of distress. Yet, a quarter of all participants reported average severe distress (n=32/ 25.4%). Demonstrating this impact, 70.7% of participants in total reported ongoing nervousness, 65% reported experiencing worry, 62.7% reported losing pleasure in previously enjoyable tasks, while 59.5% reported ongoing feelings of depression which they

linked to their eating and swallowing problems (see Table 37). Using Spearman's rho nonparametric correlation, there was a mild but significant negative inverse correlation between age and levels of nervousness (rho = -0.255, P = 0.004), worry (rho = -0.187, P = 0.036) and overall levels of distress (rho = -0.223, P = 0.012). Therefore, younger participants reported significantly higher levels of distress than older participants. No significant differences in levels of distress were found based on gender, overall, or specific symptom profiles.

Table 37: Descriptive Statistics of the PHQ-4

	Frequency of Scores - n (%)			
Variable	**Not at all**	**Several days**	**Most days**	**Nearly everyday**
Nervous	37 (29.4)	27 (21.4)	23 (18.3)	39 (31.0)
Worry	44 (34.9)	30 (23.8)	21 (16.7)	31 (24.6)
Lack of pleasure	47 (37.3)	28 (22.2)	20 (15.9)	31 (24.6)
Depressed	51 (40.5)	27 (21.4)	18 (14.3)	29 (23.0)
	Frequency of Scores - n (%)			
Variable	**No distress**	**Mild distress**	**Moderate distress**	**Severe distress**
PHQ-4 composite score	40 (31.7)	29 (23.0)	25 (19.8)	32 (25.4)

The most frequent emotional impact of eating and swallowing problems included: embarrassment about potential exposure of previously hidden difficulties (sometimes: n=31/ 24.6% / always: n=43/ 34.1%), fear of choking (sometimes: n=29/ 23% / always: n=27/ 21.4%), and a loss of interest/pleasure in eating (sometimes: n=29/ 23% / always: n=42/ 33.3%) (see Table 38). In addition, challenges to participants' sense of self were reported, with feelings of otherness or "handicap" (sometimes: n=27/ 21.6% / always: n=36/ 28.6%), and depression caused by not being able to eat what they want (sometimes: n=35/ 27.8% / always: n=33/ 26.2%). Finally, half of participants experienced anger about their eating and swallowing problems (sometimes: n=29/ 23% / always: n=36/ 28.6%).

Table 38: Descriptive Statistics of the DHI - Emotional Subscale

		Frequency of Scores - n (%)			
	Variable	**Never**	**Sometimes**	**Always**	**Median (range)**
Emotional	Embarrassed to eat in public	52 (41.3)	31 (24.6)	43 (34.1)	1 (0 - 2)
	Depressed because they can't eat what they want	58 (46.0)	35 (27.8)	33 (26.2)	1 (0 - 2)
	Don't enjoy eating as much as they used to	55 (43.7)	29 (23.0)	42 (33.3)	1 (0 - 2)
	Nervous because of swallowing problem	58 (46.0)	29 (23.0)	39 (31.0)	1 (0 - 2)
	Feel handicapped because of swallowing problem	63 (50.0)	27 (21.4)	36 (28.6)	0.5 (0 - 2)
	Get angry at myself because of swallowing problem	61 (48.4)	29 (23.0)	36 (28.6)	1 (0 - 2)
	Afraid of choking and stopping breathing because of swallowing problem	70 (55.6)	29 (23.0)	27 (21.4)	0 (0 - 2)

Patient Health Information Needs

Participants were asked if they had received sufficient information on TMD-related eating and swallowing problems from their healthcare providers (see Table 39). Almost half (n=54/ 42.85%) reported that they had not received satisfactory information on this topic. Most participants (n=124/ 98.4%) thought that receiving an educational booklet on eating and swallowing problems would be beneficial during TMD management, with 96% (n=121) reporting that the best time to

receive information is at initial assessment. Using chi-squared tests, no significant gender differences were found regarding whether a booklet would be beneficial, the best time to receive this information booklet, or the importance of all proposed criteria for inclusion in the booklet.

Table 39: Descriptive Statistics of Information Received

Information received	Overall composite prevalence
No information	42.85% (n=54)
Diagnostic term	73.61% (n=53)
Possible available treatments	25% (n=18)
Epidemiology of TMD-related eating and swallowing problems	11.11% (n=8)
Available exercises	8.3% (n=6)
Avoid parafunction	6.94% (n=5)
Information on diet modifications	4.16% (n=3)

Of the participants who reported receiving insufficient information on eating and swallowing problems during previous TMD management, 35.18% (n=19) said that the only information on TMDs that they had received was the draft patient booklet. For example: Participant 117: "*This is the first time anyone has made the connection between my jaw problem and my swallowing problem - it's like a weight has been lifted, it's the best talk I've had in years and the most helpful*"; Participant 107: "*Prior to the booklet I got little information about eating*"; Participant 95: "*Only the booklet-this is the best thing I have been given in relation to my health- it has all the information I need*"; Participant 103: "*The booklet- it's such a valuable education -learned more from this… than 10 years of doctors*". Of those who had previously received information (n=72/ 57.14%), most had only provided with the name "TMJ" (e.g.: Participants 74, 78, 80, 85, 87, 88, 89: "*Only the name "TMJ"*") (n=53/ 73.61%). The minority (n=3/ 4.16%) reported receiving information on how to appropriately consume texture modified diets (e.g.: Participant 42: "*To go on a "liquid diet"*").

Most participants perceived the receipt of all available information on eating and swallowing problems to be important (see Table 40). Participants reported that receiving information on treatments (n=123/ 98%), post-treatment follow-up care (n=123/ 98%), the prevention of recurrence (n=122/ 97%), and self-care strategies which the patient can independently use to relieve symptoms (n=122/ 97%) were most important. The information which participants least prioritised were "who gets TMD-related eating and swallowing problems and what the risk factors are" (n=4/ 3.2%), and "possible side effects of different treatments" (n=3/ 2.4%).

Table 40: Descriptive Statistics of Prioritsed Information

	Frequency of Scores - n (%)		
Variable	**Not Important**	**Somewhat Important**	**Most Important**
The specific medical name of the condition	2 (1.6)	20 (15.9)	104 (82.5)
The cause of TMD-related eating and swallowing problems	1 (0.8)	7 (5.6)	118 (93.7)
Who typically gets TMD-related eating and swallowing problems and what are the risk factors	4 (3.2)	15 (11.9)	107 (84.9)
Information on possible assessments for TMD-related eating and swallowing problems	2 (1.6)	13 (10.3)	111 (88.1)
What each assessment specifically investigates	2 (1.6)	15 (11.9)	109 (86.5)
Information on all the possible treatments for TMD-related eating and swallowing problems	0 (0)	3 (2.4)	123 (97.6)
Possible side effects of different treatments	3 (2.4)	1 (0.8)	122 (96.8)
How the treatment works to manage TMD-related eating and swallowing problems	0 (0)	4 (3.2)	122 (96.8)
Post treatment follow-up care	0 (0)	3 (2.4)	123 (97.6)
Self-care strategies that can be done at home to relieve symptoms	1 (0.8)	3 (2.4)	122 (96.8)
Coping strategies to help deal with physical and emotional consequences of TMD-related eating and swallowing problems	0 (0)	7 (5.6)	119 (94.4)
Information on prevention/management of TMD-related eating and swallowing problems recurrence	0 (0)	4 (3.2)	122 (96.8)
Useful resources and contacts for more information	1 (0.8)	13 (10.3)	112 (88.9)

In addition to the listed prompts, 71.43% (n=90) of participants also reported additional information needs (see Table 41).

Table 41: Descriptive Statistics of Further Information Required

Information Criteria	**Overall composite prevalence**
No further information required	28.57% (n=36)
Treatment options	18.25% (n=23)
Prognosis	15.07% (n=19)
Diet modifications	11.11% (n=14)
All available information	7.14% (n=9)
Epidemiology of TMD-related eating and swallowing problems	7.14% (n=9)
Surgical procedures and risks	7.14% (n=9)
Available medications and indications	6.24% (n=8)
Receiving accessible information	3.96% (n=5)
The possibility of obtaining a cure	3.12% (n=4)
Emotional coping strategies	2.38% (n=3)
The contribution of parafunction to eating and swallowing problems	2.38% (n=3)
The typical care pathway	2.38% (n=3)
The diagnostic process	1.58% (n=2)
Preventing recurrence	.79% (n=1)
Ruling out malignancy	.79% (n=1)
How to ease the pain of speaking	.79% (n=1)
The cost of treatment	.79% (n=1)

These included information regarding the long-term prognosis of TMD-related eating and swallowing problems (n=19/ 15.07%) (e.g.: Participant 117: "*How long does* [this] *typically last?*"; Participant 110: "*Will it come back again and again?";* Participant 100: "*When will I be normal again?*"; Participant 25: "*Will it get worse?*"); the need for further information regarding all available treatment options (n=23/ 18.25%) (e.g.: Participant 108: "*How can I end this?"*); information on how to ensure ongoing nutritionally adequate and satisfactory oral intake despite diet modifications (n=14/ 11.1%) (e.g.: Participant 63: "*What foods to eat and foods to avoid*"; Participant 73: "*As much info* [sic] *about eating as possible*"; Participant 81: "*How to continue eating healthily in the long term*"; Participant 112: "*Will I ever be able to eat?*"); and the importance

of receiving accessible information (n=5/ 3.96%) (e.g.: Participant 122: "*I need all general information- I Googled this and got information from the internet that was wrong and that made me hurt more* "; Participant 103: "*Easy to understand info* [sic] *like this booklet- it's such a valuable education -learned more from this research than 10 years of doctors*"; Participant 85: "*I want to know everything- I was given the name and lots of long words that I don't understand- today is the first time I have been listened to and understood*").

There was a significant overall right symptom difference regarding the information criteria of "treatment options" (chi-squared = 8.08, P = 0.018). No participant considered this item to be 'not important'. Twenty-six (96%) of the 27 participants with no right-sided symptoms considered information on possible treatments most important; 16 (89%) of the 18 participants with right masticatory muscle disorders considered it most important; and all 81 participants with TMJ disorders on the right side considered information on possible treatments to be most important. Using chi-squared tests, no significant differences were found between overall left symptoms, or specific right or left symptoms on whether an educational booklet would be beneficial, the best time to receive such a resource, or the suggested criteria.

Most participants reported specific worries about TMD-related eating and swallowing problems (n=71/ 56.34%) (see Table 42), primarily relating to symptom progression and recurrence (n=24/ 33.8%). For example: Participant 61: "*Progressing to having to eat a liquid diet*"; Participant 88: "*Will I have to live like this forever?*"; and Participant 123: "*Can I go back to normal eating ever?*". A cohort of participants were also concerned about the implications of consuming a modified diet (n=8/ 11.26%). For example: Participant 100: "*How will I cope with this diet?*" and Participant 113: "*How will I eat and cope with the hunger?*".

Table 42: Descriptive Statistics of Additional Concerns

Particular Concerns	Overall composite prevalence
No particular concerns	43.65% (n=55)
Symptom progression and recurrence	33.8% (n=24)
Requiring surgical intervention	14.08% (n=10)
Understanding treatment pathways and processes	12.67% (n=9)
Consuming a texture modified diet	11.26% (n=8)
Gaining access to reliable information	5.63% (n=4)
Side effects of intervention	5.63% (n=4)
Concerned about everything	5.63% (n=4)
Medication use	4.22% (n=3)
Requiring emergency medical or dental treatment (e.g.: intubation) and this being impacted on by their TMD	4.22% (n=3)
Experiencing pain	4.22% (n=3)
Epidemiology of TMD-related eating and swallowing problems	2.8% (n=2)
Cost of intervention	1.4% (n=1)
Cosmesis	1.4% (n=1)
The process of diagnosis	1.4% (n=1)

In addition, 5.63% (n=4) had particular concerns about gaining access to reliable and understandable information on TMD-related eating and swallowing problems. For example: Participant 44: "*Understanding what* [healthcare professionals] *tell me*"; Participant 92: "*How to deal with the lack of info* [sic]"; Participant 97: "*Learning proper info* [sic] *and being heard*". Finally, understanding treatment pathways and processes was a particular concern for 12.67% of

participants (n=9), while a cohort of participants also reported additional management concerns, ranging from the need for further information on assessment procedures (e.g.: Participant 117: "*Why am I getting continuous X-rays?"*), to concerns regarding the availability of direct treatment for these eating and swallowing problems (e.g.: *"When can I get SLT- just at the start or even now?"*) (n=4/ 3%).

6.3. Discussion

This cross-sectional study investigated the prevalence, nature, and impact of TMD-related eating and swallowing problems in treatment-seeking adults presenting to national specialist centres of care. In line with the findings of Chapter 5, this research found that secondary to masticatory impairments, eating and swallowing problems are common in this group. Findings here also suggest that these eating and swallowing problems impact on the completion of daily, social, family, and occupational activities, and that patients prioritise the receipt of information from clinicians on the management of these issues.

Masticatory impairments were commonly reported by these patients, with investigator reported assessment finding that among the 40% of the sample who were able to complete the TOMASS, participants required more masticatory cycles per bite than healthy normal individuals(226). It is hypothesized that this may be associated with reduced force and effectiveness of masticatory cycles secondary to limited TMJ ROM, pain, and fatigue. In addition, participants required more swallows than healthy normals to clear solid boluses from the oropharyngeal cavity, potentially due to boluses not being adequately masticated and causing subsequent transit difficulties. These findings may also be associated with subjective reports of participants requiring multiple swallows (n=73/ 58%), liquid washdowns (n=86/ 68%), and altered swallow movements (n=85/ 67%) to clear boluses, yet that even with these alterations, almost half yet experience a strangling sensation during swallowing (n=60/ 48%) and up to 31% (n=39) report coughing on solid boluses. This suggests the need to use IROMs of eating and swallowing in future research and practice in order to improve the accuracy of assessment and treatment provision. In addition, research is recommended to determine the need to integrate SLTs into future TMD MDTs in order to address these difficulties in eating and swallowing.

Eating and swallowing problems were reported here to result in participants taking longer to finish a meal (n=91/ 72%), modifying their diets (n=81/ 64%), eating smaller meals (n=76/ 60%), reducing their oral intake (n=68/ 54%) or avoiding oral intake altogether (n=65/ 52%). It is hypothesised that these behaviours may contribute to the 50% of individuals who reported unintentional weight loss (n=63). However, there is minimal information available on this topic, therefore warranting future research into the true oral intake of adults with TMDs, and the need for the inclusion of the dietitian in the provision of clinical care to this group.

This research provided new information on the impact of TMD-related eating and swallowing problems on physical functioning and emotional well-being. A quarter of participants reported

severe psychosocial distress associated with TMD-related eating and swallowing problems (n=32/ 25%). In addition, participants reported that eating and swallowing problems have a moderate impact on participation in daily, recreational, social, and family activities, with a median mild interference with occupational activities. As such, these issues have the potential to reduce an individual's opportunities for activity and participation in social and professional contexts, which may subsequently impact on their self-construct, identity, and self-esteem. As chronic pain conditions and psychosocial well-being are symbiotic entities(280,281), this data may inform the need for future research into the impact of these problems and investigations of their management.

Finally, with reference to management, participants reported a range of information needs about their eating and swallowing problems, spanning epidemiology, impact, and management criteria. Almost half of participants here reported that although they had typically experienced TMD-related eating and swallowing problems for 5 years, they had received no previous professional advice on the management of these issues (n=54/ 43%) and most reported that receiving such information would be beneficial to their recovery. It is hypothesised that if clinical information on eating and swallowing problems caused by TMDs, such as that provided in the new educational tool developed here, was included as a component of general TMD management, patients may experience reduced physical and emotional impact of these issues, with subsequent lower levels of reliance on healthcare structures and improved cost-effectiveness of care provision (270–272).

Study Limitations

As in the previous study (see Section 5.2.), the main limitation here was that treatment-seeking participants were recruited from national specialist centres of TMD care. Therefore, the severity of difficulties reported here may be higher than the overall group of individuals who experience TMDs, thus warranting further research within larger and more representative cohorts. In addition, the lack of normative data for the investigated orofacial variables combined with the lack of repeated measurements per variable render it difficult to compare findings both within and among patients, and indeed between patients and healthy subjects, suggesting the need for repeated measures of assessment in future studies.

Recommendations

To begin, it is recommended that further investigations of TMD-related eating and swallowing problems are conducted which recruit participants from general and community-based medical, dental, complementary, and allied health practices, in conjunction with recruitment of individuals who are self-managing symptoms, to ensure representativeness of findings. Secondly, future research is recommended to validate the new assessment protocol for clinical use. As a third point, it is also recommended that the patient data on information needs regarding TMD-related eating and swallowing problems shape the future refinement of the pilot educational booklet, in order to improve the content, readability, and accessibility of this tool. Finally, in light of the numbers of participants who could not complete the TOMASS, and the rates of reported altered

oral intake and unintentional weight changes, it is advised that published research on the use of diet modifications is explored, with the view to determine if Irish figures gathered here resemble those produced at a global level and to ultimately inform the future development of evidence-based treatment options.

6.4. Summary and Conclusions

This study demonstrated that adults with TMDs experience eating and swallowing problems as a result of masticatory impairments, thus supporting the findings of Chapter 5. However, findings here also suggest that these eating and swallowing problems impact on both functional and emotional well-being, and that patients with TMDs report a range of information needs regarding the management of these issues. A new assessment protocol for use with this group was developed here to support future clinical management. In addition, a new educational resource providing information on TMD-related eating and swallowing problems and their management was piloted, with the collection of patient feedback which will be used to further refine and develop this tool within future work.

Chapter Seven: The Use of Modified Diets by Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

7.0. Introduction

As highlighted in Chapters 5 and 6, most adults with TMDs experience masticatory impairments, with 81% reporting that they modify their diets as a compensatory strategy (see Section 5.2.). It is hypothesised that adults with TMDs who modify their oral intake may be consuming diets which are imbalanced in nutrients, minerals, vitamins, and calories. This hypothesis may be indirectly supported by the unintentional weight changes reported by participants here (see Sections 5.2. and 6.2.). However, little is known about the extent of diet modifications or their use as a compensatory strategy in this group. Therefore, a systematic review with meta-analysis was conducted to further examine the prevalence of diet modification use among adults with TMDs within published research (e.g.: avoidance of certain foods or consumption of a soft/pureed/minced moist diet to accommodate masticatory impairments) (see Appendix 29).

7.1. Methods

The methods used to investigate the consumption of texture modified diets by adults with TMDs will be presented below, with subsequent examination of data gathered and findings generated.

Study Design

This systematic review was carried out in line with the PRISMA(247) and MOOSE(282) guidelines. A systematic review, as opposed to a prospective study, was conducted to examine if data collected here on the extent of diet modifications among adults with TMDs resembled that of internationally published estimates, or if figures here were elevated potentially due to participants being recruited from national specialist centres of care.

Eligibility Studies

All available published and unpublished evidence which provided data on the prevalence of modified diet use in adults with TMDs was eligible for inclusion. No restrictions on language, research location/setting, or publication date were applied. Case reports were not eligible for inclusion due to their low levels of evidence.

Eligible Participants

Data was sought on adults (aged 18 years and older) presenting with TMDs who reported use of this compensatory strategy, with no eligibility restrictions applied (e.g.: sex, race, disease duration, severity, age-of-onset, or recruitment location). Individuals were excluded if they reported a history of congenital, orthopaedic, traumatic, or cancerous conditions affecting the structure and/or function of the oral and maxillofacial area.

Search Strategy

A systematic search strategy which accounted for filters, key-text and medical subject headings, was employed across 9 electronic databases by 2 independent reviewers. The databases searched were: EMBASE, PubMed, CINAHL, Web of Science, Elsevier Scopus, Science Direct, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. Databases were searched from inception to January 2017, with all results exported using the Zotero reference management software (Zotero Software, George Mason University, USA). The titles and abstracts of all identified records were screened by 2 independent reviewers, with obviously ineligible studies excluded. Hand-searches were conducted in line with those discussed in Section 4.1., in conjunction with searches of the reference lists of eligible studies, available grey literature, and the Google Scholar database as additional measures.

Data Extraction Process and Data Items

An electronic data extraction form previously piloted (see Section 4.1.) was used by 2 independent reviewers, with a third reviewer available to mediate disputes, if required. Full consensus on extracted data was reached. In the case of missing/unclear data, the researcher contacted corresponding authors of primary studies published in the previous 10 years (see Section 4.1.), with exclusion of studies in the case of no response to 2 contact attempts.

Assessment of Methodological Quality

The methodological quality of included studies was rated by 2 independent reviewers using the Downs and Black assessment tool(254) (see Appendix 7).

Summary Measures and Synthesis of Results

Descriptive analysis was initially conducted, with subsequent statistical analysis using Microsoft Excel (Microsoft, Richmond, WY, USA) and the MedCalc Systems for Windows, version 15.0 (MedCalc Software, Ostend, Belgium) to conduct both fixed and random effects meta-analyses of estimates(257). Figures were presented using 95% CIs and displayed using forest plots.

7.2. Results

The findings of this systematic review and meta-analysis will be presented in the following sections.

Study Identification

In total, searches of electronic databases resulted in 10248 identified records (see Figure 21).

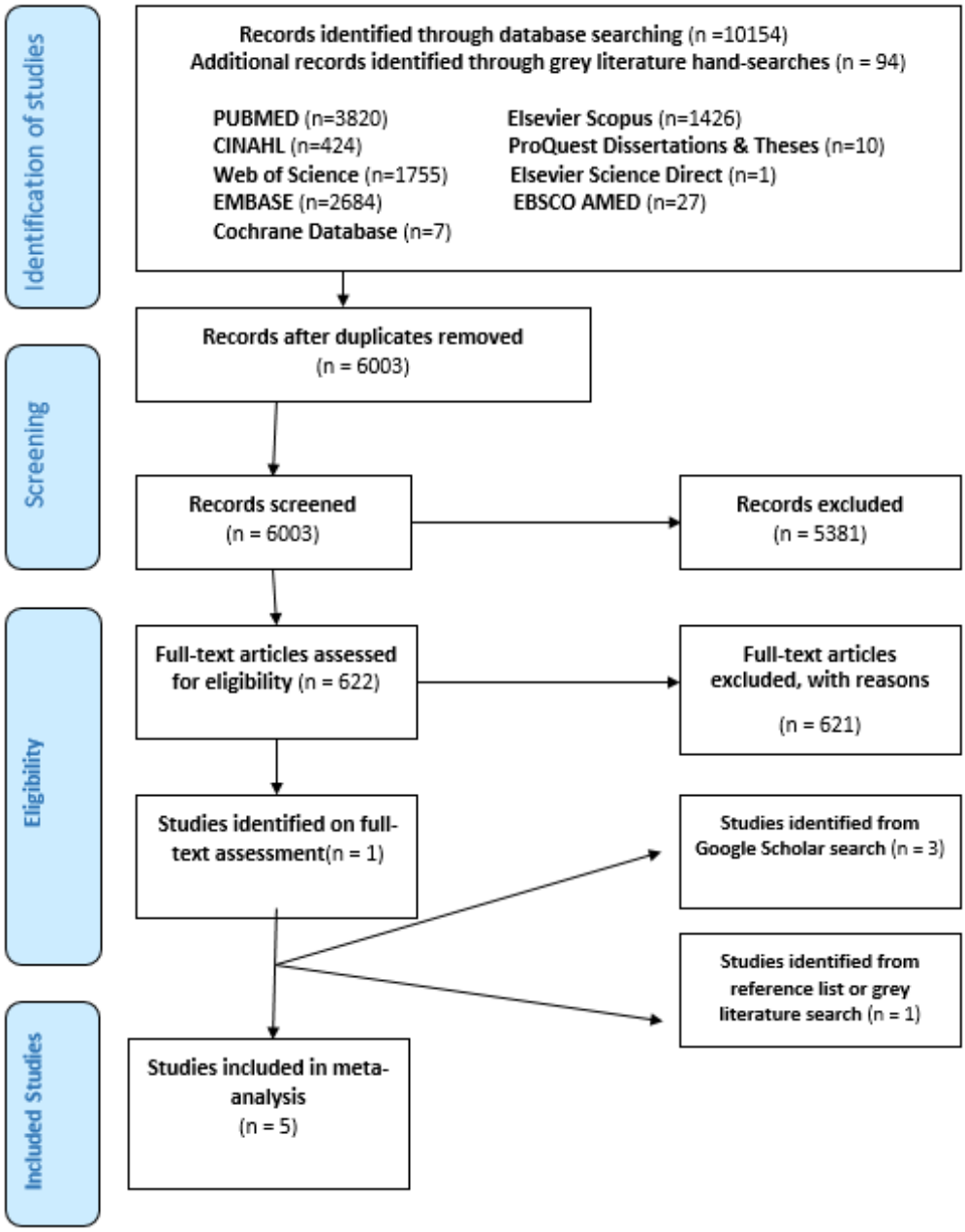


Figure 21: PRISMA Diagram

Subsequent to the exclusion of duplicates and obviously ineligible results, 622 full-text studies were reviewed by 2 independent reviewers, resulting in the identification of 1 eligible study(121). Additional Google Scholar searches resulted in identification of 3 further eligible articles(119,123,126), with reference list searching identifying 1 subsequent study(116). Missing data or lack of access to articles was addressed with 3 contact attempts relating to missing data and 2 relating to requesting access to articles. In total, 5 articles were included in the meta-analysis.

Participant Demographics

Data pertaining to 533 patients were included, with an overall mean age of 36 years of age (see Table 43). No included study provided participants' age ranges. In total, 420 females and 113

males (3.71:1 / female:male) were eligible for inclusion. Included studies varied as to whether they reported 1 primary symptomatic classification per overall participant or 1 classification per unilateral TMJ. MFP was the most frequently reported symptom (n=266), while DDs were also commonly reported (DDWR: n=156 / DDWOR: n=55 / DDWOR and arthralgia: n=34). Arthralgia was common (n=141), while a small cohort experienced OA (n=27) or osteoarthrosis (n=9).

Characteristics of Included Studies

The characteristics of included studies are described in Table 43. The majority of eligible studies were cross-sectional (n=2/40%) or case-control studies (n=2/40%), with 1 study being classed as an RCT (n=1/20%). The location of eligible studies were broad, including Northern Europe (n=2/40%), South America (n=1/20%), and Asia (n=1/20%). The setting of most included studies were university hospital clinics (n=4/80%). Outcome measurement tools included the RDC/TMD(148) (n=5/100%) and subjective patient-reported questionnaires (n=5/100%). Only 1 study assessed masticatory performance to investigate chewing across a range of food textures(121).

Table 43: Characteristics of Included Studies

Citation	Year of publication	Region from which participants were recruited	Setting from which participants were recruited	Period of recruitment	Study design	No. of patients with TMDs studied	Female: male ratio	Mean age (SD) of patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (months)	Relevant outcome measured	Sources of assessment data	Study quality score
Baker et al.,(126)	2015	Sweden	University clinic	36 months	RCT	34	10.3:1	38.9 (+- 15)	Unclear	49.1 (unclear)	Diet modifications: 11.8%	RDCTMD, X-ray, MRI, IMMPACT questionnaire, VAS, JFLS-8, GCPS, SCL-90R	15/18
Foteder et al.,(123)	2015	India	University hospital clinic	6 months	Cross-sectional	83	5.91:1	34.8 (+- 17.2)	Unclear	Unclear	Diet modifications: 53.1%	RDC/TMD, patient interviews, case history, OHIP-14	12/18
Barros et al.,(119)	2008	Brazil	University clinic	4 months	Cross-sectional	132	4.92:1	36.5 (+-13.5)	Unclear	Unclear	Diet modifications: 50.6%	RDC/TMD, OHIP-14, clinical exam, Temporomandibular Index	13/16
Brandini et al.,(121)	2011	Australia	Unspecified hospital	Unclear	Case-control	15	15:0	31.3 (+-10.8)	Unclear	Unclear	Diet modifications: 60%	RDC/TMD, chewing task, numerical rating scale-II, Pain Self-efficacy Questionnaire, Fear-Pain Questionnaire-III, DAS-44, PCS	13/18
Reißmann et al.,(116)	2007	Germany	University clinic	66 months	Case-control	318	3.16:1	38.6 (+-15.6)	Unclear	Unclear	Diet modifications: 55%	RDC/TMD, German version of OHIP, GCPS, Beschwerden-Liste, the Center for Epidemiologic Studies Depression Scale	10/18

Assessment of Methodological Quality of Included Studies

Using the Downs and Black tool(254), reviewers reached full consensus regarding ratings of methodological quality. On average, studies with a comparison group were judged to be of moderate quality, while those without a comparison group were rated to be of good quality (see Tables 15, 16, and 17). The items which contributed to lower methodological quality ratings were: inadequate descriptions/measurement of confounding factors and inadequate blinding. A range of items contributed to positive ratings, including: adequate description of null hypotheses/aims and the use of valid and reliable outcome measurement tools.

Prevalence of Diet Modifications

Based on data extracted from 5 studies (n=533)(116,119,121,123,126), the prevalence of diet modification use was estimated to be 45.1% (CI: 31.93-58.64) (see Figure 22).

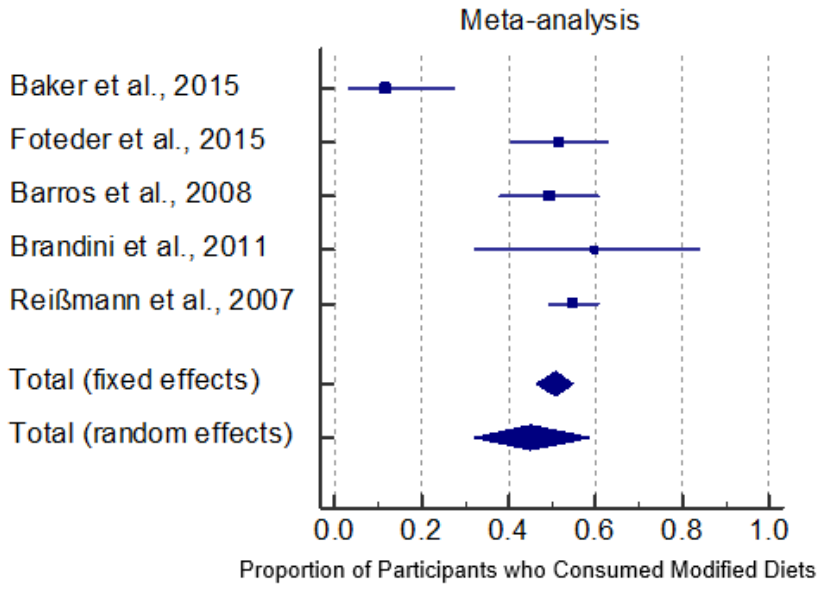


Figure 22: Forest Plot of Prevalence of Diet Modifications

7.3. Discussion

Diet modifications are commonly used as a compensatory strategy by individuals with TMDs who experience impaired mastication. Research on eating and swallowing problems in other clinical cohorts suggests that consuming a modified diet negatively affects overall physical health. In addition, HRQOL is also often affected as food choices are restricted and participation in social events is reduced(260,283). However, little is known about the impact of diet modifications in adults with TMDs on physical functioning and psychosocial well-being.

It is hypothesised that if diets are modified, they may not be nutritionally balanced and may lack key nutrients or calories. Research has found that the modified diets consumed by people with eating and swallowing problems typically contain significantly lower levels of energy and protein than those consumed by healthy controls(260). In addition, patients consuming modified diets

also demonstrate significantly greater energy and protein deficits than healthy controls, potentially increasing the risk of unintentional weight loss(260). Finally, modified diets often contain higher levels of sugar(284) and lower levels of fibre than recommended(285), with the potential for the development of subsequent gastrointestinal difficulties, such as constipation(286). In other clinical groups who experience eating and swallowing problems, the dietitian typically evaluates and manages these potential risks to weight and systemic health, as part of the wider MDT(287,288). However, it is unclear if patients with TMDs typically have access to dietitians during TMD management.

Study Limitations

The primary limitations were the limited number of studies which satisfied the strict inclusion criteria, and the lack of population-based studies available for inclusion. Therefore, true prevalence rates may be different to estimates presented here. Also, only 1 study used masticatory assessments to determine the most appropriate levels of oral intake(121). Therefore, the use of subjective questionnaires in the majority of included studies may under-estimate levels of reliance on/need for modified diets, with ultimate impact on the accuracy of prevalence figures. As such, it is recommended that large scale, population-based research using subjective assessments and IROMs are conducted to further our understanding of these issues.

Recommendations

It is advised that subsequent research addresses a range of issues, including:

1. Examination of the true dietary intake of adults with TMDs to determine if they are consuming the recommended levels of nutrients, vitamins, and energy(161);
2. Investigation of the potential systemic and psychological implications of consuming texture modified diets within this cohort; and
3. Investigation of the need to include professionals such as the dietitian in future TMD MDTs.

7.4. Summary and Conclusions

This study re-iterated that adults with TMDs commonly use diet modifications as a compensatory strategy to accommodate masticatory impairments. It is hypothesised that these individuals may not be consuming nutritionally balanced diets in accordance with international guidelines, thus introducing the potential for secondary health and social consequences. Therefore, further evidence-based research is required to examine the true dietary intake of individuals with TMDs and to subsequently determine the most appropriate methods of supporting these individuals to maintain healthy and balanced levels of oral intake.

Section Three

As discussed, it is hypothesised that adults with RA may experience more severe eating and swallowing problems than those with non-inflammatory TMDs (see Section 1.3.2.). However, limited research has been previously conducted to investigate this hypothesis. In Section 3, the methods and results of research conducted to investigate eating and swallowing problems in adult patients with RA will be presented.

Chapter Eight: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders associated with Rheumatoid Arthritis: A Systematic Review and Meta-analysis

8.0. Introduction

As outlined, it is suggested that patients with RA-related TMDs may experience eating and swallowing problems at a greater degree and severity than those with non-inflammatory TMDs (see Section 1.3.2). Throughout this research, participants with RA reported a range of eating and swallowing problems associated with TMDs. However, limited numbers of these patients were recruited (see Sections 5.2. and 6.2.), limiting the representativeness of findings. Therefore, to further examine the prevalence and nature of eating and swallowing problems within this patient group, a systematic review with meta-analysis of the available evidence on this topic was conducted (see Appendix 30).

8.1. Methods

The methods used to conduct this study will now be described in subsequent sections.

Study Design

This study was conducted using the same design as Chapter 4 with regards to exclusion criteria, outcomes investigated, data management, and analytical techniques (see Section 4.1.). The protocol was prospectively published on the University of York Centre for Reviews and Dissemination Prospero database (Registration number: CRD42016033528)(289).

Eligible Studies

All randomised and non-randomised, published and unpublished articles investigating the epidemiology of eating and swallowing problems associated with TMDs in adults presenting with RA were eligible for inclusion, with no language, demographic, geographic, or date limitations.

Eligible Participants

Studies on adults aged 18 years and older presenting with eating and swallowing problems associated with RA affecting the TMJ were included if they were diagnosed with RA as per the American Rheumatism Association(290) or ACR/European League against Rheumatism classification systems(291).

Search Strategy

The search strategy was developed with TCD librarians and systematically employed to the databases searched in Chapter 4 (see Section 4.1.) (see Appendix 31). Grey literature was examined to detect previously undiscovered eligible information. Hand-searches of the annual scientific meetings of the ACR (published in *Arthritis and Rheumatology*) and the International

Association for Dental Research (published in the *Journal of Dental Research*) were also conducted during February 2016. Reference lists of included studies and the Google Scholar database were subsequently hand-searched to further identify any records not indexed in directories initially searched.

Summary Measures and Synthesis of Results

Overall pooled prevalence estimates, with 95% CIs, were initially determined. Subsequently, prevalence figures as per primary and secondary outcomes were produced using descriptive statistics. A meta-analysis using a random-effects model for the primary analysis, and a fixed-effect model as a sensitivity analysis was conducted in collaboration with a TCD data analyst, using the R statistical package (R core team, 2013, Austria) (Version 2.14.0). Forest plots were produced for all outcomes.

8.2. Results

Findings of this systematic review and meta-analysis will be presented in the following section.

Study Identification

A total of 11616 results were retrieved (see Figure 23). All records were exported to the Zotero reference management software (Zotero Software, George Mason University, USA), with 3561 duplicate records excluded. Three independent reviewers screened a third of the remaining titles and abstracts each, and excluded 7923 obviously ineligible results. A fourth reviewer independently mediated disputes if they occurred. A total of 132 full-text records were subsequently examined. At this stage, 114 of these full-text records were excluded. Supplementary Google Scholar searches identified 1 further eligible study(177). No additional eligible articles were identified from reference list or grey literature searches.

Overall, 43 contact attempts to 30 researchers were made regarding 20 studies. For 2 of these studies, missing data was sought, while 18 communications related to article access. Contact led to 6 eligible studies, the exclusion of 7 irrelevant studies, and 2 studies were excluded due to insufficient data. Five studies were excluded due to an inability to contact authors. Ultimately, 19 studies satisfied the inclusion criteria, had data extracted, and were included in analysis.

Participant Demographics

Data regarding 1400 patients presenting with RA were extracted across 19 studies (see Table 44). The pooled age range of patients with RA was 18-82 years, although 7 (36.8%) of the included studies did not provide sufficient details on participant ages.

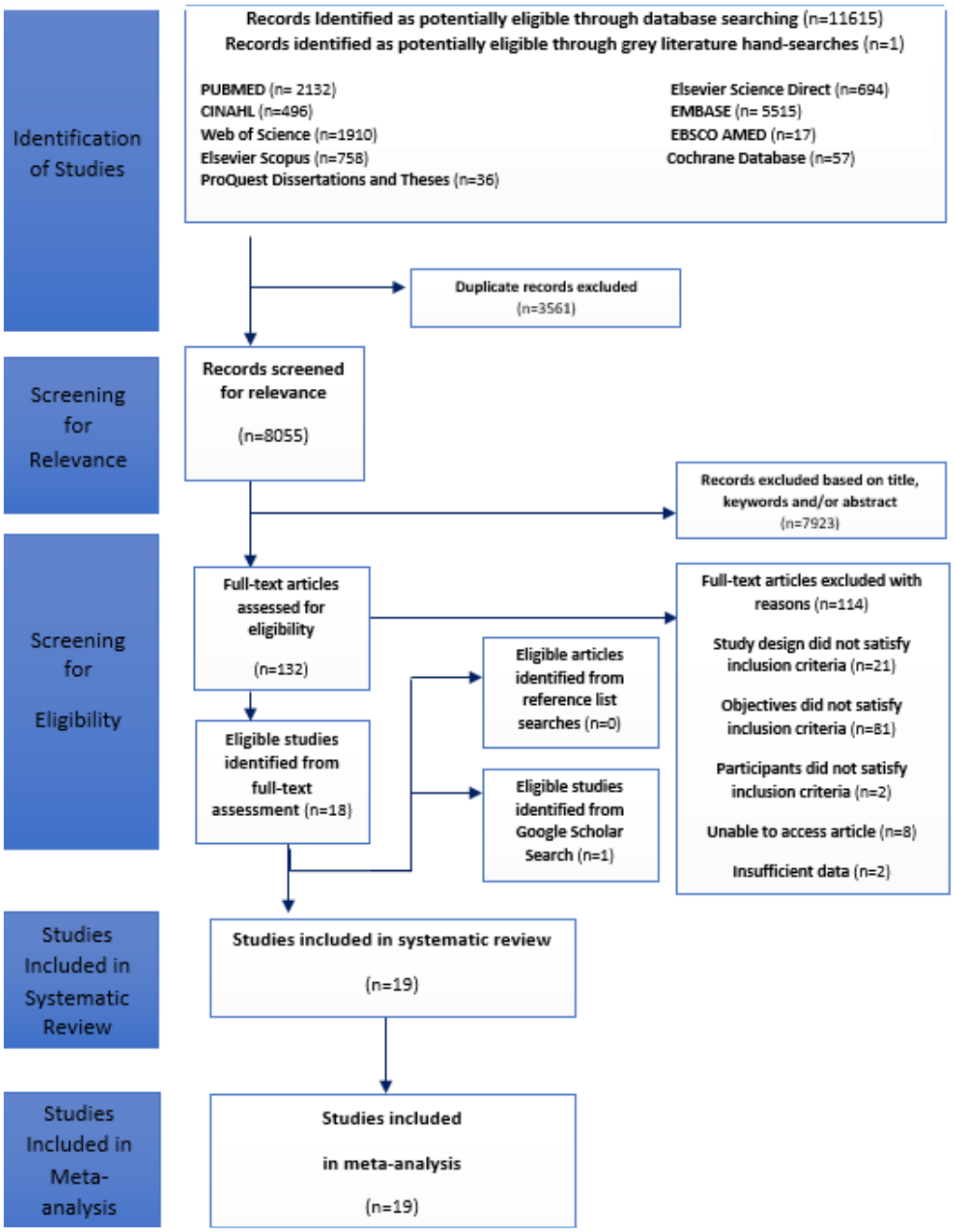


Figure 23: PRISMA Diagram

Table 44: Characteristics of Included Studies

Citation	Year of publication	Region from which participants were recruited	Setting from which participants were recruited	Year of recruitment	Study design	No. of patients with TMDs studied	Female : male ratio	Mean age (SD) of patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (years)	Main outcome measured	Sources of assessment data	Study quality score
Franks(166)	1969	England	Rheumatology Hospital	Unclear	Case-control	100	3:1	Unclear	Unclear	Unclear	Impaired mastication: 69%	Subjective questionnaire, clinical exam, X-ray, computed tomography (CT)	12/16
Chalmers & Blair(172)	1973	Unclear	Unclear	Unclear	Case-control	100	3:1	Unclear (18-77)	42(16-73)	11(0.2-47.0)	Masticatory pain: 10%	Clinical exam, CT	11/18
Ogus(174)	1975	England	General hospital	Unclear	Case-control	62	2.8:1	Unclear (21-79)	Unclear	Unclear	Masticatory pain: 36%	Clinical exam, patient interviews, CT	11/18
Larheim et al.,(165)	1983	Sweden	Health centre	Unclear	Case-control	49	4:1	58 (Unclear)	36(17-75)	22(1-49)	Impaired mastication: 2.04%	Clinical exam, patient interviews, X-ray	8/18
Ekberg et al.,(186)	1987	Sweden	Radiology and Internal Medicine Department, University Hospital	Unclear	Descriptive observational	31	4.1:1	Unclear	Unclear	Unclear	Impaired swallowing: 33.3%	Cineradiography	7/16
Tegelberg (185)	1987	Sweden	Rheumatology Hospital	1982-1983	Case-control	151	4:1	Unclear (21-82)	Unclear	Unclear	Masticatory fatigue: 55%	Dental and medical history, clinical dysfunction score, Eichner Index, Helkimo Anamnestic Index, Ritchie Index, Lee Index, erythrocyte sedimentation rate, C-reactive protein, Skin surface temperature measurements	14/18
Könönen et al.,(175)	1992	Sweden	Rheumatology Department, University Hospital	Unclear	Case-control	61	7:1	Unclear (24-80)	Unclear	Unclear	Masticatory pain: 25%	Subjective questionnaire, clinical exam, Helkimo Anamnestic Index	8/18
Goupille et al.,(178)	1993	Unclear	Unclear	Unclear	Case-control	26	5.5:1	62.1(50.3-73.9)	53.3(39.3-67.3)	8.7(5-51)	Masticatory pain: 19.23%	Clinical exam, patient interviews, CT	11/18

El-Assy et al.,(177)	1994	Egypt	Rheumatology Department, University Hospital	Unclear	Case-control	30	9:1	Unclear	Unclear	Unclear (1-20)	Masticatory pain: 50%	Case history, clinical TMJ exam, ENT exam, direct and indirect laryngoscopy, audiological evaluation, laboratory blood testing, radiological assessment	16/18
Kallenberg et al.,(170)	1997	Sweden	Rheumatology Department, University Hospital	Unclear	Case-control	81	10.5:1	56.1(22-80)	Unclear	Unclear	Impaired swallowing: 30.86%; Masticatory fatigue: 20%; Impaired mastication: 31%; Masticatory fatigue: 19%	Subjective questionnaires, Helkimo Anamnestic Index, Body Symptom Scale, Mood Adjective Checklist	15/18
Voog et al.,(173)	2003	Estonia	Stomatology Clinic, University Hospital	Unclear	Descriptive observational	19	8.5:1	Unclear	Unclear	Unclear	Masticatory pain: 95%	ADL scale, rheumatoid factor, erythrocyte sedimentation rate, C-reactive protein; VAS, clinical exam, electronic pressure algometer	11/16
Helenius et al.,(162)	2005	Finland	Rheumatology Department, University Hospital	September 1996 – August 1998	Case-control	24	11:1	48.9(37.5-60.3)	Unclear	10.5(7.9-13.1)	Masticatory pain: 42%	Subjective questionnaire, clinical and stomatognathic exam, X-ray	16/18
Bessa-Nogueira et al.,(150)	2008	Brazil	Rheumatology Department, University Hospital	December 2003 – December 2004	Descriptive observational	61	9:1	Unclear (24-76)	Unclear	Unclear	Impaired mastication: 39.3% Impaired swallow: 13.10%	Clinical exam, patient interviews, Health Assessment Questionnaire, VAS	11/16
Yilmaz et al.,(167)	2012	Turkey	Rheumatology Department, University Hospital	Unclear	Case-control	28	13:1	Unclear (35.51-52.49)	Unclear	Unclear	Impaired mastication: 37.9%	Clinical examination, erythrocyte sedimentation rate, C-reactive protein, rheumatoid factor, DAS-28, X-ray, MRI	12/16

Aceves-Avila et al.,(169)	2013	Mexico	Rheumatology Department, University Hospital	September 2010-February 2011	Case-control	92	Unclear	Unclear	Unclear	Unclear	Impaired mastication: 26%	Subjective questionnaire, clinical exam, case history	15/18
Ahmed et al.,(176)	2013	Saudi Arabia	Rheumatology Department, University Hospital	Unclear	Descriptive observational	33	7.25:1	Unclear	Unclear	Unclear	Masticatory pain: 74%	Clinical exam, DAS-28. Blood sampling, VAS	13/16
Bono et al.,(168)	2014	Argentina	Rheumatology Department, University Hospital	Unclear	Case-control	95	5:1	45(24-74)	Unclear	10.5(2-39)	Impaired mastication: 23.24%	Clinical exam, DAS-28, Health Assessment Questionnaire, X-ray	10/18
Ahola et al.,(163)	2015	Finland	Database of Finnish Rheumatism Association	Unclear	Cross-sectional	282	Unclear	Unclear	Unclear	Unclear	Impaired mastication: 54.25%; Masticatory pain: 12.41%; Masticatory fatigue: 6.02%	Subjective questionnaire, OHIP-14	16/18
Hoyuela et al.,(164)	2015	Brazil	Rheumatology Department, University Hospital	July 2010 – February 2012	Cross-sectional	75	Unclear	Unclear	Unclear	Unclear	Impaired mastication: 17.3%	Clinical exam, dynamometer, OHIP-14, DAS-28, dynamometer, Health Assessment Questionnaire, Disabilities of the Arm, Shoulder and Hand questionnaire	15/18

Characteristics of Included Studies

Thirteen studies were case-control studies (68.42%), 4 were descriptive observational studies (21.05%), and 2 were cross-sectional studies (10.52%). Study locations included South America (n=3/15.78%), Central America (n=1/5.26%), Europe (n=11/57.89%), Africa (n=1/5.26%), and the Middle East (n=1/5.26%). University hospital rheumatology clinics were the setting of 10 studies (52.63%). Sixteen studies (84.21%) employed clinical stomatognathic evaluations and/or case histories and interviews (n=7/36.84%) in assessment. Questionnaires investigating symptoms, HRQOL, or participation (e.g.: the DAS-28(292) or the OHIP-14(293)) were used in 10 studies (52.63%). IROMs, such as X-rays (n=7/36.84%), CT (n=3/15.78%), laryngoscopy (n=1/5.26%), and MRI (n=1/5.26%), were used in several studies.

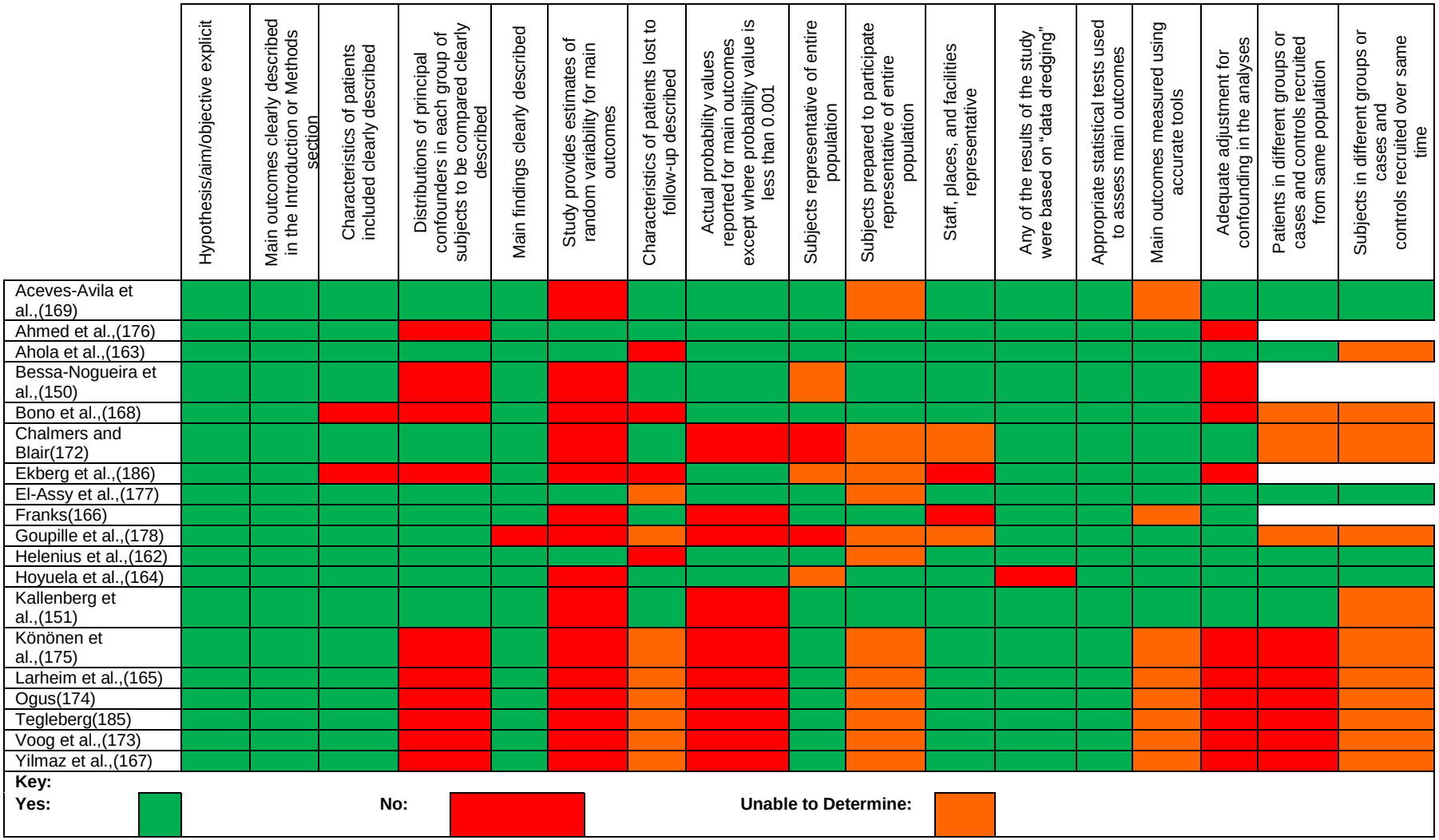
Assessment of Methodological Quality of Included Studies

Independent reviewers reached 100% consensus regarding assessment of methodological quality. The methodological quality of included studies was primarily rated using the Downs and Black Checklist(254) (see Tables 45 and 46). On average, studies with a comparison group were awarded a score of 12.8 out of a possible 18 points, and were rated as moderate quality. Studies without a comparison group were awarded an average score of 11 out of a possible 16 points, and were also awarded an average rating of moderate quality. Methodological quality was also rated using the hybrid Boyle-JBI tool. Ratings awarded using the Downs and Black tool and amended Boyle-JBI tool were highly correlated, with both tools providing overall average ratings of moderate quality (see Appendix 32).

Table 45: Downs and Black Checklist Scoring of Included Studies

Study name	Score awarded	Comparison group	Rating awarded
Aceves-Avila et al.,(169)	15/18	Yes	Good
Ahmed et al.,(176)	13/16	No	Good
Ahola et al.,(163)	16/18	Yes	Good
Bessa-Nogueira et al.,(150)	11/16	No	Moderate
Bono et al.,(168)	10/18	Yes	Moderate
Chalmers and Blair(172)	11/18	Yes	Moderate
Ekberg et al.,(186)	7/16	No	Fair
El-Assy et al.,(177)	16/18	Yes	Good
Franks(166)	12/16	No	Good
Goupille et al.,(178)	11/18	Yes	Moderate
Helenius et al.,(162)	16/18	Yes	Good
Hoyuela et al.,(164)	15/18	Yes	Good
Kallenberg et al.,(151)	15/18	Yes	Good
Könönen et al.,(175)	8/18	Yes	Fair
Larheim et al.,(165)	8/18	Yes	Fair
Ogus(174)	11/18	Yes	Moderate
Tegleberg(185)	14/18	Yes	Moderate
Voog et al.,(173)	11/16	No	Moderate
Yilmaz et al.,(167)	12/16	No	Good

Table 46: Downs and Black Methodological Quality Risk of Bias Table



The main items responsible for lower ratings of methodological quality were:

1. Lack of provision of estimates of random variability regarding main outcomes (n=14/73.68%);
2. Lack of description of the distribution of confounding factors (n=7/36.84%);
3. Lack of adequate accounting for confounding factors within statistical analysis (n=7/36.84%); and
4. Lack of provision of sufficient details to determine if samples were representative of the target population (n=11/57.89%).

Items contributing to positive quality ratings were:

5. Clear statements of hypothesis/aims/objectives and main findings (n=19/100%); and
6. Use of appropriate statistical tests to assess main outcomes (n=19/100%).

Prevalence of TMD-related Eating and Swallowing Problems

Impaired mastication was reported in 9 studies(150,163–170) (n=863). This prevalence estimate was calculated to be 30.69% (95% CI: 19.24-45.14%) (see Figure 24).

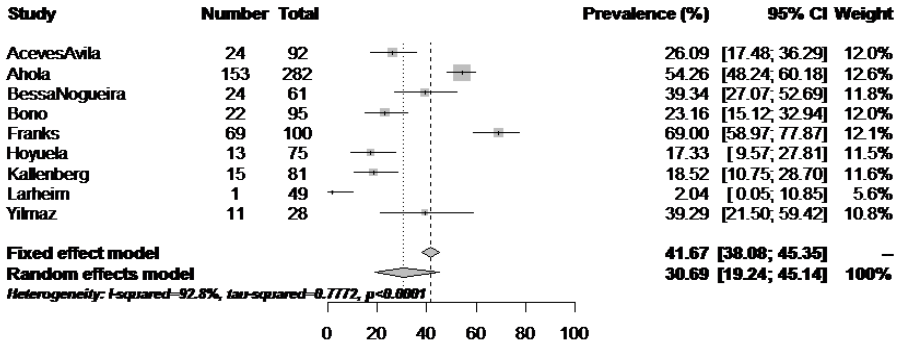


Figure 24: Forest plot of the Prevalence of Impaired Masticatory Ability

Masticatory pain was reported in 9 studies(162,163,172–178) (n=637), with this prevalence estimate calculated to be 29.97% (95% CI: 17.13-46.99%) (see Figure 25).

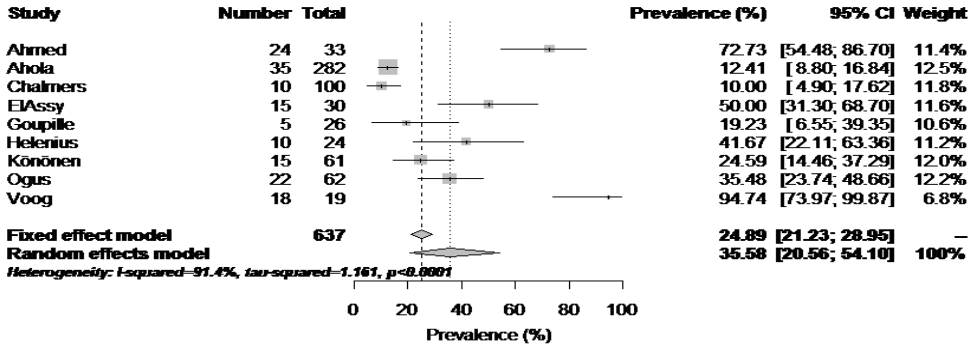


Figure 25: Forest plot of the Prevalence of Pain on Mastication

Masticatory fatigue was reported in 3 studies(151,163,185) (n=514). This prevalence estimate was calculated to be 21.26% (95% CI: 4.10-63.01%) (see Figure 26).

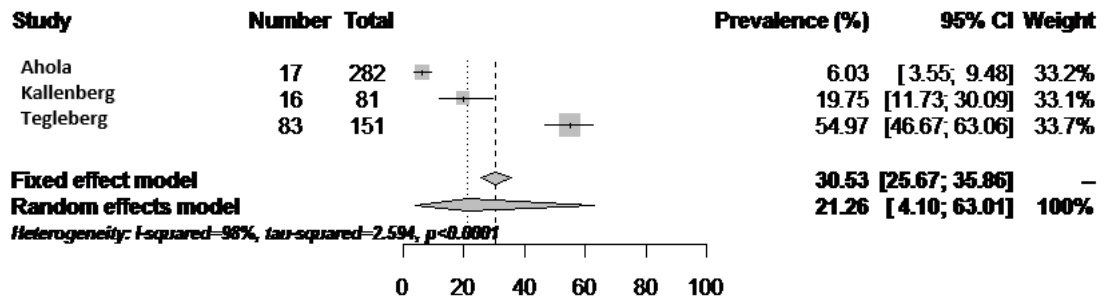


Figure 26: Forest plot of the Prevalence of Fatigue on Mastication

Based on data from 3 studies(150,151,186) (n=173) the prevalence of impaired deglutition was estimated to be 24.63% (95% CI: 14.21-39.2%) (see Figure 27).

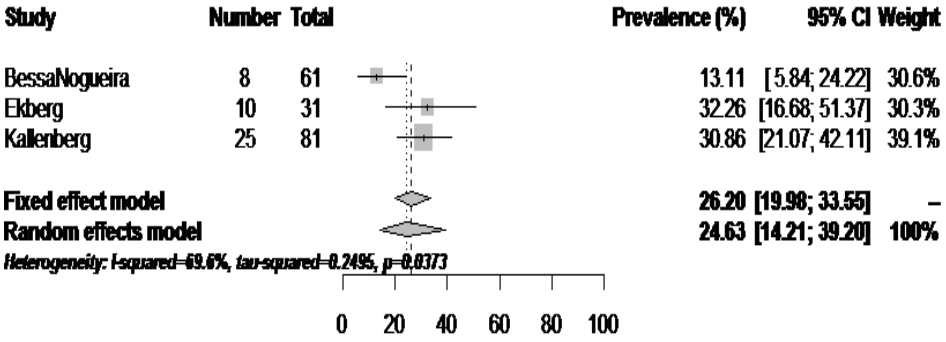


Figure 27: Forest plot of the Prevalence of Impaired Deglutition

Although specified as an outcome of interest, the prevalence of weight loss was not reported in any available eligible study.

8.3. Discussion

The findings of this systematic review and meta-analysis re-iterate that eating and swallowing problems are reported by adults presenting with RA-related TMDs, although limited research attention has historically been afforded to this condition. The disease processes involved in RA can cause occlusal changes and restricted TMJ movement, both of which can impair mastication(294). Impaired mastication was estimated in approximately 31% of patients with RA. However, methodological limitations in primary studies render it difficult to determine true prevalence rates. For example: Larheim et al.,(165) described impaired chewing in 1 patient, yet no information was available regarding whether more patients were affected. Yilmaz et al.,(167) also reported chewing difficulties in 38% of patients with RA, but it is unclear if difficulties were present in controls, and there were no responses to attempts to access supplementary data. As

such, the provision of full data sets would improve future investigations of the epidemiology of masticatory difficulties in this group.

Individuals with RA may also experience masticatory impairments secondary to pain on chewing. Masticatory pain may be related to RA inflammatory joint destruction, internal derangement, capsule stretching, synovitis, and muscle tenderness. This study estimated that a third of individuals with RA experience masticatory pain, as compared to the 87% of patients with non-inflammatory TMDs who experienced this issue in the previously discussed systematic review (see Section 4.2.), therefore, challenging the hypothesis that RA may induce masticatory pain to a greater degree than non-inflammatory based TMDs. However, it is hypothesised that patients with RA may receive disease-modifying pharmacological intervention which reduces pain, as compared to those with non-inflammatory conditions. Therefore, it is warranted that this parameter is further investigated to explore this hypothesis to a greater degree. Expanding on the topic of masticatory impairments, global and chronic fatigue originates from the pain, sleep difficulties, and emotional disturbances which often accompany RA(182). The prevalence of specific masticatory fatigue in this group was calculated here to be 21%. It is recommended that masticatory fatigue in individuals with RA is investigated further as it has been shown within non-TMD cohorts to result in lengthened mealtimes, reluctance to eat in public, and reduced HRQOL(295).

The primary outcome, impaired deglutition, was present in 25% of patients with RA-related TMDs. However, included studies were characterised by methodological limitations which restrict the validity and reliability of results. Notably, 2 of the 3 included studies which addressed swallowing(150,151) used only subjective questionnaires, while only 1 used IROM imaging tools(186). Therefore, the true prevalence of swallowing problems in this group may be higher than estimated here, thus emphasising the need for future research into the epidemiology, nature, impact, and management of swallowing problems in adults with RA-related TMDs.

Finally, weight loss is a frequent consequence of eating and swallowing problems in non-RA populations, potentially resulting in malnutrition, increased risk of infection and depression, and reduced wound healing(260). Weight loss can also increase the severity of eating and swallowing problems by reducing muscle and nerve function(260). While anecdotal evidence of TMD-related weight loss exists, no studies addressing this outcome were identified. Therefore, investigation of this parameter is warranted. Also, it is hypothesised that the involvement of dietitians and SLTs in future care provision to this group may be beneficial in specifically addressing eating and swallowing problems caused by TMDs.

Study Limitations

One key limitation was that few available studies met the strict inclusion criteria. For example: case reports were excluded due to their limited evidence and propensity for bias. This led to the exclusion of several records which may have influenced estimates, despite methodological

limitations. Also, few eligible studies used IROMs, with the subjective assessments used having varied psychometric properties. Finally, conclusions are based on a small number of heterogeneous studies. As such, reported frequencies are only estimates and true prevalence figures may be different to those presented here. Therefore, future prospective epidemiological investigation of these parameters is warranted.

Recommendations

This systematic review indicated that within the available literature, individuals with RA-related TMDs report eating and swallowing problems. However, few individuals were referred to the 2 specialist centres of care over the entire 18 month cross-sectional prospective study period in the research here (see Sections 5.2. and 6.2.), and it is unclear how these problems are currently managed by the rheumatologist. As such, it is recommended that the perspectives and typical practices of rheumatologists who manage TMDs in adults presenting with RA are investigated. In addition, findings of this study also support the need to validate the new assessment tools developed here for use with individuals with TMDs (see Sections 5.2. and 6.2.), with further research into the development of specialist tools for the management of eating and swallowing problems in patients with inflammatory-based TMDs also warranted.

8.4. Summary and Conclusions

This study suggested that eating and swallowing problems are reported by adults presenting with RA of the TMJ within previously published literature, and highlighted that limited amounts of heterogeneous research has been conducted on these problems. It is hypothesised here that this lack of research may lead to limited professional awareness of these issues, with potential impact on clinical management provided. This study therefore emphasized the need for further research into the epidemiology, nature, impact, and management of TMD-related eating and swallowing problems in adults with RA in order to inform future care provision.

Chapter Nine: Rheumatologists' Perspectives regarding Eating and Swallowing Problems associated with Rheumatoid Arthritis in Adults with Temporomandibular Disorders

9.0. Introduction

Both the systematic review and cross-sectional patient studies here suggest that adults with RA experience inflammatory TMDs with the potential to develop secondary eating and swallowing problems (see Sections 5.2., 6.2., and 8.2.). However, there is limited available information on how these issues are managed in clinical practice by the rheumatologist. Therefore, to examine the typical management of eating and swallowing problems in adults with RA-related TMDs, the perspectives of rheumatologists working in the Irish healthcare system were investigated.

9.1. Methods

The sections below will outline the methods used to conduct this study, with emphasis on study design, eligibility criteria, recruitment and sampling procedures, and data collection and analysis methods.

Study Design

A cross-sectional survey design was used to investigate rheumatologists' perspectives on the significance of TMD-related eating and swallowing problems in adults with RA, the typical processes involved in MDT care provision to these patients, and respondents' satisfaction with service delivery. This study was conducted in line with the methods of Chapter 3 (see Section 3.1.). Ethical approval was granted by the TCD SLSCS to conduct this study (see Appendix 33).

Participants

Medical doctors with specialist rheumatology training who were currently/had previously been involved in the management of adults with RA-related TMDs within the Irish healthcare system (inclusive of the Republic of Ireland and Northern Ireland) were eligible for participation in this study if they were members the Irish Society for Rheumatology (ISR), regardless of year of qualification, specialist education age, or sex. The ISR is the representative professional organization for clinicians with specialist rheumatology training who are working in the Irish healthcare system, with a membership of approximately 150 clinicians.

Sampling and Recruitment Strategies

Purposive sampling methods were used in this study. The Executive Officer of the ISR acted as gatekeeper in disseminating a standardized email to all ISR members during the study period (4 weeks in March 2017) (see Appendix 34). This standardized email contained information on the study and a link to the online survey which was hosted by the SurveyMonkey.com platform (see Appendix 35). Potential participants were invited to contact the researcher or research supervisor

with additional queries, or to complete the online survey immediately. Completion of the survey implied consent and took approximately 5 minutes.

Materials used in Data Collection

The 13-item survey used in this study was based on the tool used in Chapter 3 (see Section 3.1.), with minor amendments made to reflect the demographics of the intended sample (e.g.: changes to questions about profession) (see Appendix 35). The final version sought anonymous information on participants' demographic details, clinical experience, and perceived significance and typical management of eating and swallowing problems in adults with RA affecting the TMJ.

Data Processing and Analysis

Quantitative and qualitative data were extracted and analyzed in line with the methods outlined in Chapter 3 (see Section 3.1.).

9.2. Results

In total, 16 rheumatologists participated in this survey, with 10 completing it in full, yielding a 62.5% completion rate. While most participants (n=12/75%) reported greater than 15 years of overall clinical experience (range: 0- >15 years), only 43.75% (n=7) had clinical experience in the management of patients presenting with RA and subsequent TMD-related eating and swallowing problems. The reported locations of clinical practice were varied (see Figure 28).

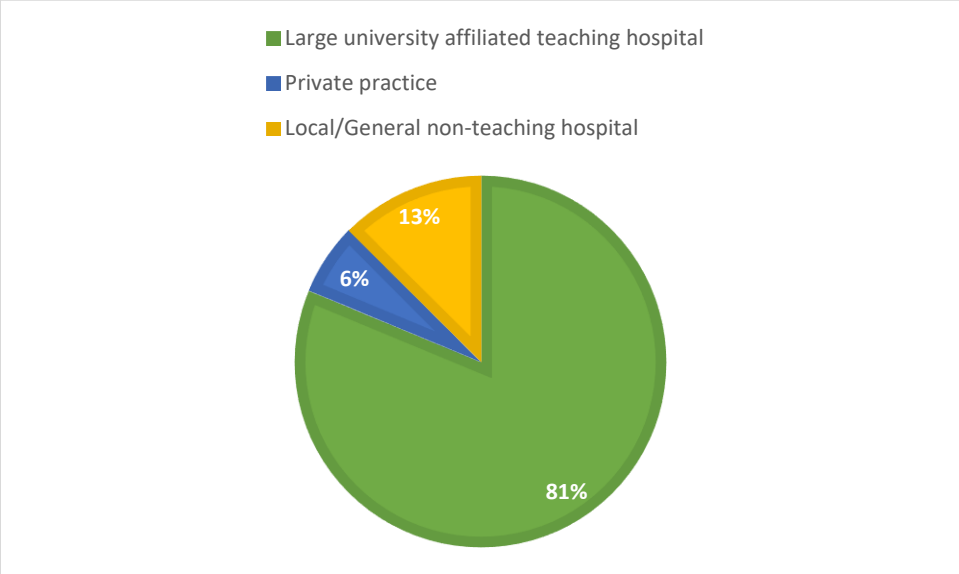


Figure 28: Reported Locations of Clinical Practice

The Significance of TMD-related Eating and Swallowing Problems in adults with RA

A total of 87.5% (n=14) of rheumatologists considered eating and swallowing problems in adults with RA to be of some significance (slightly significant: n=13/81.25% / significant: n=1/6.25%).

Perspectives on Typical Service Delivery: Assessment

Rheumatologists were asked if they assess for eating and swallowing problems in adult patients with RA. Only 6 participants completed this section in full. Most rheumatologists who answered this question (n=4/ 66.67%) do not typically assess for these issues (disagreed: n=3/50% / strongly disagreed: n=1/16.67%). When rheumatologists do assess for eating and swallowing problems in adults with RA, they typically adopt a combined approach of subjective clinical examinations (n=4/ 66.67%) and IROM imaging techniques (n=2/33.3%) (see Figure 29).

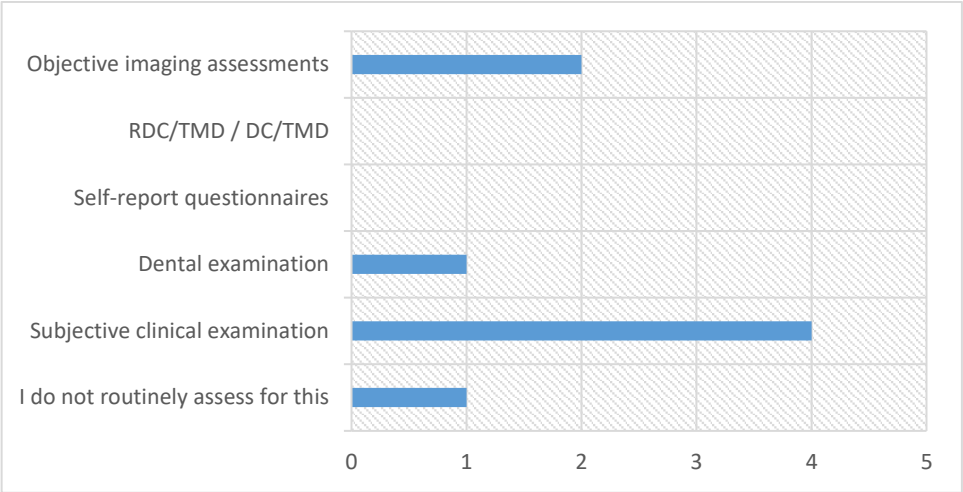


Figure 29: Assessment Methods used by Respondents

Two thirds of rheumatologists (n=4/66.67%) would not deviate from their typical RA assessment protocol to assess for eating and swallowing problems, while half (n=3/50%) were unsure if they would refer a patient with RA and eating and swallowing problems for a VFSS. All participants who completed this section (n=6) reported that they would facilitate a referral to clinical specialists if eating and swallowing problems were suspected (e.g.: SLTs and dietitians). Finally, rheumatologists were asked if they were satisfied with available assessments for TMD-related eating and swallowing problems, with 50% (n=3) reporting dissatisfaction, and 50% (n=3) reporting that they were uncertain if they were satisfied with available tools. Among the rheumatologists who reported specialised clinical experience with these patients, 66.6% (n=4) were dissatisfied with available assessments.

Perspectives regarding Typical Service Delivery: Treatment

Half of the rheumatologists who completed this section do not typically treat eating and swallowing problems in adults with RA (n=3/50%). Rheumatologists who do provide intervention for eating and swallowing problems use a range of treatments. The most frequently used treatments were: compensatory measures such as diet modifications (n=2/33.3%), patient education and counselling (n=1/16.67%), non-swallow exercises (e.g.: chewing activities) (n=1/16.67%), occlusal appliances (n=1/16.67%), and surgery (n=1/16.67%) (see Figure 30). A third of participants used combinations of treatments with this group (n=2/33.3%).

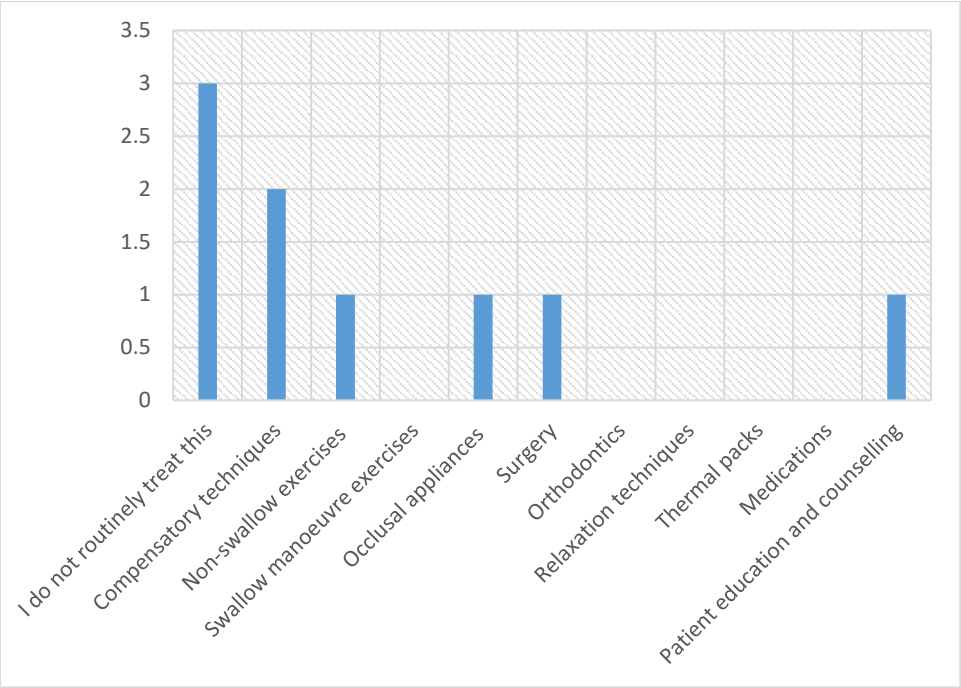


Figure 30: Treatment Methods used by Respondents

The clinical outcomes which rheumatologists considered important when treating eating and swallowing problems in adults with RA were also investigated. All participants who completed this section (n=6) agreed that improved swallowing and chewing were important outcomes (strongly agreed: n=5/83.33% / agreed: n=1/16.67%). Similarly, improved oral intake and ROM were considered important by all participants (n=6). In addition, all participants agreed that improving masticatory pain was important (strongly agreed: n=4/66.67% / agreed: n=2/33.33%), while 50% (n=3) agreed that decreasing masticatory fatigue was also important (strongly agree: n=1/16.67% / agree: n=2/33.3%). Changes in occlusion and parafunctional behaviours were considered important by 66.67% (n=4). Patient education and the improvement of HRQOL were also considered important clinical outcomes by most rheumatologists (n=5/83.3% and n=6/100%, respectively).

Finally, rheumatologists' satisfaction with available treatments for eating and swallowing problems in adults with RA was also investigated, with 50% (n=3) reporting dissatisfaction and 50% (n=3) reporting that they were unsure about their levels of satisfaction. All rheumatologists with specialised clinical experience who completed the survey in full (n=5) were dissatisfied or uncertain if they were satisfied (disagree: n=2/40% / unsure: n=3/ 60%), with qualitative reasons for dissatisfaction presented below.

Perspectives regarding Typical Service Delivery: MDT Working Patterns

No participant reported working in isolation when managing patients with RA and TMD-related eating and swallowing problems. SLTs, dietitians, and GDPs were the most common MDT members with whom rheumatologists typically liaised (n=5/83.3%). Among the other reported professionals were OMFS (n=3/50%), gastroenterologists (n=2/33.3%), and radiologists

(n=2/33.3%). Rheumatologists were also asked if there were MDT members with whom they want to increase their current levels of liaison. While a third of respondents (n=2/33.3%) reported satisfaction with their current levels of MDT interaction, a third (n=2/33.3%) would like to increase their liaison with SLTs and occupational therapists.

Perspectives regarding Typical Service Delivery: Overall Quality of Care

Levels of satisfaction with overall standards of care typically provided to adult patients with RA and TMD-related eating and swallowing problems were varied, with 33.3% (n=2) reporting that they were satisfied, 33.3% (n=2) reporting dissatisfaction, and a further 33.3% (n=2) who were uncertain about this criteria. Among the rheumatologists with specialised clinical experience, a third (n=2/33.3%) were dissatisfied, a third (n=2/33.3%) were satisfied, and a third (n=2/33.3%) were unsure if they were satisfied with current care provision.

Two themes emerged during the coding of the qualitative data (see Table 47). A total of 6 participants completed this section.

Table 47: Themes of Qualitative Data

Theme	Example
Perceived low prevalence of eating and swallowing problems in adults with RA-related TMDs	A third (n=2/33.3%) of participants reported that they perceive eating and swallowing problems in adults with RA-related TMDs to occur infrequently (e.g.: Participant 15: *"[These problems are] actually very rare in modern rheumatology practice*")
The need for greater MDT support	Half (n=3/50%) of participants emphasised the need for increased MDT interaction and support when managing eating and swallowing problems in adults with RA-related TMDs (e.g.: Participant 9: "*[We should] refer to SLT and Max Fax surgery* [OMFS] *for advice*"; Participant 12: *"[must] engage with multiple specialists";* Participant 12: *"[Patients need] correct services"*)

9.3. Discussion

This study surveyed rheumatologists working in the Irish healthcare system and sought their perceptions on the significance of eating and swallowing difficulties in adults with RA-related TMDs, the management techniques they typically use with this group, and their satisfaction with current standards of service delivery. A limited number of rheumatologists were recruited to take part in this survey, with potential impact on representativeness of findings. Despite limitations, findings suggest that surveyed clinicians' awareness of these eating and swallowing problems is low, secondary to patients with RA presenting with multiple systemic weight-bearing joint difficulties and the limited previous research in this field. As such, clinical involvement in the provision of care to these patients is also currently low. These barriers to management may result in patients not receiving targeted intervention for eating and swallowing difficulties, with the potential for the development of symptom chronicity. Therefore, further research into the epidemiology, nature, impact, and management of eating and swallowing difficulties in adults with RA-related TMDs is warranted

As in the survey of dental professionals' perspectives (see Section 3.1.), clinicians here emphasised the need for greater MDT integration and collaboration when managing eating and

swallowing difficulties in patients with RA-related TMDs. A third of clinicians surveyed here reported a desire to integrate the SLT to a greater extent into typical TMD MDTs, a finding which parallels the 100% of surveyed clinicians who prioritised improvements in swallowing, chewing, and oral intake during the management of these patients. While the sample recruited here was limited, this data may help inform the need for future expansions of clinical and research teams to address the potential for adults with RA-related TMDs to develop eating and swallowing difficulties.

Study Limitations

As in Chapter 3 (see Section 3.1.) this survey was piloted on SLTs, while rheumatologists were the intended participants. Therefore, terms used in questions here may not be appropriate for use with this group, and refinement of this tool may be required in future work. In addition, this survey had a small sample size (n=16) and low completion rate (62.5%) impacting on the representativeness of findings. Therefore, recruitment of a larger cohort of rheumatologists in future surveys is required to improve the generalisability of findings.

Recommendations

As noted, dissemination of this survey to a larger, more representative group of rheumatologists is warranted to improve the generalisability of findings. In addition, it is recommended that MDT structures are expanded to integrate clinicians with specialist skills in this area, and that cohort-specific trans-disciplinary tools for use in the management of adults with RA-related TMDs and eating and swallowing difficulties are developed to support MDT care provision in this field. Finally, this study re-iterated the high levels of diet modifications used by these patients. However, as discussed, limited research has been conducted to quantify the extent to which these modifications are used, despite hypothesised risks to nutrition and weight. As such, further investigation is warranted to examine the extent and impact of this behaviour among adults with RA.

9.4. Summary and Conclusions

This survey recruited a small number of rheumatologists with diverse experience in the provision of care to adults with RA-related TMDs and eating and swallowing difficulties. Of the rheumatologists who participated, few were typically involved in care provision to this patient group, and of those who were, many had negative perceptions regarding the tools and techniques available for use with these patients and the standards of management provided. Avenues for future research in this field were identified here, with the view to inform the future provision of care to patients with TMD-related eating and swallowing difficulties caused by RA.

Chapter Ten: The Use of Diet Modifications by Adults with Rheumatoid Arthritis affecting the Temporomandibular Joint: A Systematic Review

10.0. Introduction

This research highlighted that adults with RA-related TMDs frequently experience impaired mastication, and that two thirds of these individuals modify their diets to accommodate these difficulties (see Section 5.2.). The nutritional content of these modified diets are unknown, and it is hypothesised that they may be nutritionally imbalanced, with the potential for reduced amounts of energy and protein(260). Therefore, the use of this compensatory strategy may increase the risk of weight changes in this group, with the potential for overall impact on physical and emotional well-being. Currently, there is limited available information on the extent of diet modifications or their use as a compensatory strategy by adults with RA-related TMDs. As such, a systematic review was carried out to investigate the prevalence of diet modification use by this patient group within previous research (e.g.: avoidance of certain foods or consumption of a soft/pureed/minced moist diet to accommodate masticatory impairments).

10.1. Methods

The methods used to investigate the prevalence of texture modified diet use in adults with RA will be presented below.

Study Design

This systematic review was conducted in line with the PRISMA(247) and MOOSE(282) guidelines, with the aim of determining if prospective data collected here regarding the use of this compensatory strategy is representative of international prevalence estimates published in previous research.

Eligible Studies

All available published and unpublished evidence providing data on the consumption of texture modified diets by adults with RA of the TMJ was eligible for inclusion. No restrictions regarding recruitment locations/research settings, language, or publication date were applied. Case reports were excluded due to their low levels of evidence.

Eligible Participants

Data was sought on adults (aged 18 years and older) presenting with RA affecting the TMJ who consume modified diets, with no limitations regarding gender, age of onset, disease duration, or disease severity. Individuals were not eligible if they had a history of congenital, traumatic, carcinogenic, or neurological conditions affecting the oral, maxillofacial, or head and neck area.

Search Strategy

Two independent reviewers systematically employed a search strategy across 9 electronic databases (see Section 8.2.). This search strategy accounted for database-specific indexing factors such as filters, key-text terms, and medical subject headings, as appropriate. The Zotero reference management software (Zotero Software, George Mason University, USA) collated all retrieved results, and 2 independent reviewers deleted duplicates and screened all identified records to exclude irrelevant articles. Hand-searches of the annual scientific meetings of the International Association for Dental Research (published in the *Journal of Dental Research*) and the ACR (published in *Arthritis and Rheumatology*), the Google Scholar database, grey literature, and the reference lists of studies ultimately included were also conducted.

Data Extraction Process and Data Items

A previously piloted electronic form (see Section 4.1.) was used in data extraction by 2 independent reviewers(253). If data from studies published within the previous 10 years was missing/unclear, authors were contacted using standardised email templates, with exclusion on no response following 2 contact attempts.

Assessment of Methodological Quality

Assessments of methodological quality were conducted by 2 independent reviewers, with a third available to mediate disputes, if required. Ratings were completed using the Downs and Black Tool(254) (see Section 4.1.).

Summary Measures and Synthesis of Results

Descriptive analysis was conducted using Microsoft Excel (Microsoft, Richmond, WY, USA).

10.2. Results

The findings of this systematic review will now be presented below.

Study Identification

Searches of electronic databases yielded 11616 records. Duplicates were then deleted using the Zotero reference management software, and 2 independent reviewers assessed the eligibility of 8055 articles based on their abstracts, titles, and key words. In total, 132 full-texts were examined, leading to the exclusion of 131 records. No additional articles were identified via supplementary Google Scholar, reference list, or grey literature searches. Therefore, 1 article was ultimately included in analysis (see Figure 31).

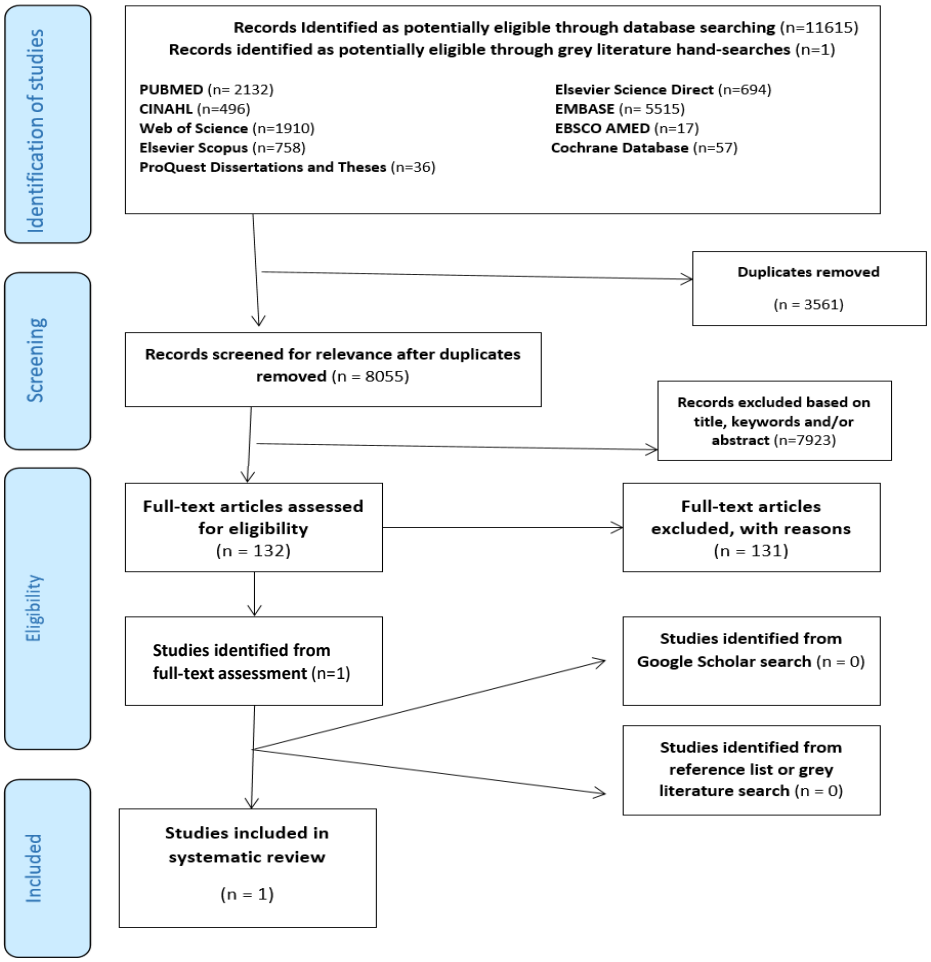


Figure 31: PRISMA Diagram

Participant Demographics

Data regarding 61 individuals presenting with RA was included, with a mean age of 44.7 years (range: 24-76)(150) (see Table 44). The data had a higher proportion of females (n=55) than males (n=6) (female: male = 9:1).

Characteristics of Included Study

Study characteristics are displayed in Table 44. The design of the included study was descriptive observational, with research conducted in the Rheumatology Department of a Brazilian university hospital(150). Data was gathered using a range of subjective assessments, including: clinical examinations, patient interviews, VAS, and the Health Assessment Questionnaire(296).

Assessment of Methodological Quality of Included Study

Independent reviewers reached 100% consensus on methodological quality assessments, with the included study being rated as moderate quality (11/16) (see Tables 45 and 46).

Prevalence of Diet Modifications

Based on data extracted from 1 study (n=61)(150), the prevalence of diet modification use was estimated to be 50.82% (CI: 37.7-63.86).

10.3. Discussion

Although diet modifications were commonly used by patients with RA-related TMDs in the prospective studies here (see Sections 5.2. and 6.2.), this systematic review identified that minimal research has been previously conducted on this topic at an international level. As discussed in Chapter 7, the use of diet modifications to accommodate masticatory impairments in other clinical cohorts is associated with reduced physical and emotional well-being (see Section 7.3.). Therefore, future research on the consumption of modified diets by adults with RA-related TMDs is warranted to determine the impact of this compensatory strategy and to inform future care provision to this group.

Research suggests that impaired physical mobility(297,298) and the use of certain pharmacological interventions (e.g.: anti-tumour necrosis factor)(299) may put individuals with RA at risk of unintentional weight changes. In addition, the metabolic repercussions of RA may also cause unintentional weight changes (see Section 1.3.2.). Therefore, adults with RA who also consume modified diets which may not be nutritionally optimal(285) may be at further risk of weight changes, reduced physical functioning, and decreased HRQOL. Therefore, these individuals may experience overall decreases in systemic health and well-being as a result of using this compensatory strategy. Within other clinical cohorts, the dietitian works as part of the broader MDT to assess and minimize such risks to nutrition and weight. However, there is limited available information on the role of the dietitian in the management of adults with RA-related TMDs, therefore suggesting a potential avenue for future investigations.

Study Limitations

The main limitation of this systematic review was that only 1 study met the pre-specified eligibility criteria, and therefore, the true extent of modified diet consumption among adults with RA-related TMDs may be different to figures presented here. Therefore, it is advised that further research on this topic is carried out with representative cohorts in order to supplement the professional knowledge base and inform future care provision.

Recommendations

It is recommended that future research in this field investigates:

1. The true rate of modified diet use by this patient group;
2. The typical oral intake of adults with RA-related TMDs to assess if the nutritional and calorific content is sufficient and in accordance with international guidelines;

3. The potential systemic, nutritional, and psychological impact of consuming a texture modified diet in the context of inflammatory disease; and
4. The need to include dietitians in typical MDT care provision to adults with RA-related TMDs.

10.4. Summary and Conclusions

This study highlighted that limited information is available on the use of modified diets by adults with RA-related TMDs. It is hypothesised that use of this compensatory strategy is common among this group, and that consuming a modified diet may impact on physical and emotional well-being and introduce the risk of unintentional weight changes. Therefore, future research into the use of diet modifications by adults with RA-related TMDs is recommended to investigate the frequency and methods of diet modifications, the nutritional values of these diets, and any potential additional risks to well-being and functioning which their consumption may introduce.

Section Four

The following chapter will discuss the overall findings, implications, recommendations, and conclusions of this research.

Chapter Eleven: Overall Discussion of Research Findings

11.0. Introduction

The catalyst for this research was the hypothesis that the masticatory impairments, pain, and fatigue commonly reported by adults with TMDs may cause subsequent eating and swallowing problems, with potential impact on physiological functioning and emotional well-being. However, due to the profile of these patients, their lack of acute hospitalisations, and the limited research which has been conducted in this field, it was hypothesised that eating and swallowing problems would potentially be perceived as insignificant and that clinical management would be limited. Therefore, this research examined the epidemiology, nature, impact, and management of eating and swallowing problems in adults presenting with non-inflammatory and inflammatory TMDs. Within this chapter, overall findings will be discussed, with consideration of the potential implications of these results for future research and clinical practice. This chapter closes with recommendations for future action and the overall conclusions of this research.

11.1. The Epidemiology and Nature of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

This research generated new information on the epidemiology and nature of eating and swallowing problems in adults with TMDs. Throughout this research, a core set of clinical issues were iteratively investigated, as will now be discussed.

Masticatory Dysfunction

It is established that impaired mastication and associated pain and fatigue are commonly experienced by adults with TMDs (see Sections 4.2. and 8.2.). Yet, these are typically viewed as issues affecting the oral preparatory stage of swallowing alone, and research on potential consequences for overall eating and swallowing is limited. In addition, there are few available assessment protocols or rehabilitation options for clinicians to use specifically with patients with TMDs who experience chewing difficulties. Therefore, these factors combine to reduce both clinician and researcher awareness of the existence or potential implications of these issues.

While research has previously established that masticatory dysfunction is common in this group, investigations here generated new findings on the specific nature of these problems. For example, masticatory difficulties were reported to impact on the typical oral intake of up to 89% of participants, with a quarter even reporting difficulty masticating food that requires little/no effort (see Section 5.2.). In addition, 90% of participants experienced masticatory pain, and 78% reported fatigue, with this subsequently resulting in most individuals taking longer to eat meals (72%), and having reduced meal endurance (60%) (see Sections 5.2 and 6.2.). Objectively, this research found that patients with TMDs require more masticatory cycles per bite than healthy normal individuals(226) (see Section 6.2.). It is hypothesised that this is potentially related to restricted ROM in patients with TMDs, which may subsequently affect bite force and masticatory

effectiveness. Also, requiring more masticatory cycles per bite may be associated with the high levels of fatigue and pain experienced by this group, as greater levels of effort may provoke greater levels of discomfort.

New findings were also generated here on masticatory dysfunction as experienced by patients with inflammatory and non-inflammatory conditions. For example: discrepancies in the prevalence of masticatory pain were reported between groups, with 97% of individuals with MFP experiencing this discomfort, as compared to 50% of patients with RA (see Section 5.2.). These trends may relate to: the expansion of receptive fields and pain amplification thought to contribute to dysfunction in non-inflammatory TMDs (See Section 1.2.1.), and the possibility that individuals with RA were prescribed disease-modifying medications to control inflammation and pain. While these trends do not reach statistical significance, potentially due to small sample sizes, they do suggest the need for treatments targeting the specific pathological processes associated with these disorders.

Impaired Swallowing

The central hypothesis of this research was that adults with TMDs experience impaired mastication which has potential repercussions for overall eating and deglutition, due to the overlap between swallowing stages. Support for this hypothesis was generated here, with up to 53% of adults with TMDs reporting some degree of swallowing difficulty (see Section 6.2.). The median severity of swallowing difficulties in this group was moderate, although half of all participants reported severe difficulties. The most commonly reported swallowing problems were: requiring liquid washdowns (68%) and multiple swallows (58%) secondary to oral residue and oropharyngeal transit difficulties. In addition, half of participants experience strangling sensations on swallowing (48%), causing a third to cough when swallowing foods (31%), and total regurgitation of solid boluses in 41% of participants, as they were unable to swallow un-masticated boluses. Adding support to these subjective findings were the investigator reported results which indicated that adults with TMDs require on average more swallows per bite, and demonstrate less time per swallow than healthy normative values(226). It is hypothesised that higher frequency swallowing may be related to poor mastication, formation, and cohesion of the bolus, resulting in piecemeal deglutition and oropharyngeal transit difficulties. This highlights the symbiotic nature of masticatory and deglutitive processes and suggests the need to consider all potentially contributing factors to impaired eating and swallowing in adults with TMDs, in order to inform future care provision.

Comparison of findings from participants with inflammatory and non-inflammatory TMDs demonstrated that although overall median levels of the severity of swallowing difficulties were similar, these issues were reported at a higher rate among participants with RA. For example: trends suggest that while 100% of participants with RA reported “sometimes” choking, experiencing strangling sensations during swallowing, and having to swallow again to clear residue, only 21%, 22%, and 26% of the overall sample experienced these difficulties (see Section 6.2.). It is hypothesised that the higher levels of swallowing difficulties among adults with RA may

be related to: 1) joint destruction which impedes mastication and causes more severe secondary oropharyngeal transit difficulties in adults with RA than those with non-inflammatory symptoms, or 2) the effects of RA disease processes at the glottic level which may complicate this clinical profile. In addition, limited numbers of participants with RA were recruited here, with potential impact on the representativeness of findings. Also, information on the prevalence and nature of swallowing difficulties was collected here relying primarily on patient-reported outcomes and completion of the orofacial exam and TOMASS protocol, due to the nature of oral preparatory difficulties in this group. However, inherent limitations to these methods exist, including subjective recall and reporting bias, and the lack of total participation in the TOMASS. It is therefore suggested that to address these difficulties within future research, bedside swallow examinations which include oral trials of a range of different textures and/or mealtime observations of typical oral intake are included, in order to examine true patient performance across a range of functional swallowing contexts.

Despite these limitations, in light of the minimal previous research which has been conducted to investigate these issues, the new information and suggestions for subsequent research generated here on impaired swallowing in adults with TMDs may inform future developments in clinical practice and research in this field, with potential positive consequences for the provision of patient-centred care.

Unintentional Weight Changes

Finally, the epidemiology and nature of unintentional weight changes were also investigated in this research. It was hypothesised here that impaired masticatory and associated pain and dysfunction may cause adults with TMDs to alter/cease typical oral intake, with resultant unintentional impact on weight. However, no previous research had been conducted on this topic, and it was therefore unanticipated that half of all participants here would report unintentional weight loss (see Section 6.2.), while almost a fifth reported weight gain (see Section 5.2.).

While 50% of participants reported weight loss (see Section 5.2.), the majority also reported total cessation of oral intake during TMD symptom flare-ups (85%) (see Section 5.2.), whereas 60% reported frequently eating smaller meals, and 54% reported frequently eating less when symptoms were at their most severe (see Section 6.2.). These findings potentially support the hypothesised body-wide impact of impaired mastication on oral intake and ultimate weight levels in this group. Furthermore, participants presenting with conditions involving chronic systemic dysfunction reported the highest rate of reduced oral intake (e.g.: DJD: 100% and myalgia: 100%). This may be related to the lack of refractory periods which these patients experience, as compared to conditions such as DDWR which fluctuate in presence and severity (see Section 5.2.). Therefore, food avoidance and subsequent weight loss may be more frequent among patients presenting with chronic TMDs. As unintentional weight loss has the potential to further exacerbate these systemic difficulties and impact on HRQOL, recovery, clinical outcomes, and the cost-effectiveness of management, these findings highlight the need for the early prevention of food avoidance among these patients.

In contrast, almost a fifth of participants here (17%) reported unintentional weight gain which they attributed to consuming an imbalanced diet primarily consisting of convenience and non-nutritionally balanced foods (see Section 5.2.). Support for this finding was provided by the majority of participants who reported consuming modified diets without guidance from dietitians (81%), thus introducing the potential for unmanaged secondary complications. As increased BMIs augment the risk for secondary cardiovascular, endocrine, orthopaedic, and respiratory conditions, patients with TMD-related eating and swallowing problems may be at a higher risk of developing systemic complications. In light of these preliminary findings, it is therefore advised that further investigations of the epidemiology, nature, and implications of unintentional weight gain in this group are conducted, to address potential morbidity risks, and to improve service delivery and patient experience and recovery.

Comparison of findings suggest that adults with RA may experience lower levels of weight loss (17%) than those with non-inflammatory symptoms (see Section 5.2.). However, it is hypothesised here that as patients with RA in this research were referred to the sampling locations from specialist rheumatologists, they may have received previous treatment which supported them in avoiding unintentional weight loss. For example: disease modifying anti-rheumatic medication which may have subsequently reduced the need to consume modified diets or avoid eating, as compared to patients with non-inflammatory conditions who did not necessarily receive previous specialist intervention. However, despite the lower prevalence of weight loss in this cohort, this issue yet warrants future research attention as weight loss and malnutrition in this group impact negatively on HRQOL, functioning, and life expectancy(189,190).

Although 67% of adults with RA reported consuming modified diets which are potentially nutritionally imbalanced, weight gain was not reported by any participants with RA-related TMDs. However, this finding does not necessarily imply that weight gain is not experienced by cohort, as individuals with RA may experience unintended increases in body fat levels in the absence of discernible weight gain due to muscle wasting secondary to systemic inflammation (see Section 1.3.2.). Therefore, further research into the typical and optimal body composition of adults with RA-related TMDs is required, as in the absence of noticeable increases in body weight, reduced cardiovascular and systemic functioning may go undetected, with negative effects on functioning and well-being.

11.2. The Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Chronic pain conditions such as TMDs impact directly on patient functioning and HRQOL(38,77,163,281,300,301), while also indirectly affecting those within their social networks and the broader community as a whole(171,281). Furthermore, eating and swallowing problems caused by respiratory, oncological, neurological, and orthopaedic aetiologies negatively influence patient morbidity and mortality(268,295,302,303). Therefore, it was hypothesised here that if adults with TMDs experience eating and swallowing problems which are not effectively managed,

there may be the potential for negative impact on physical functioning, psychosocial well-being, and HRQOL. As such, in this research, the specific impact of eating and swallowing problems in adults with TMDs was investigated.

Participants here reported that the mean time since the onset of their eating and swallowing problems was 5 years, and that these issues have a moderate median impact on their completion of daily, recreational, social, and family activities, and a mild median interference with typical occupational activities. Eating and swallowing problems provoked a range of negative emotional reactions among participants. For example: a quarter of all participants reported frequent severe emotional distress associated with eating and swallowing (see Section 6.2.). In addition, a high level of anhedonia specifically associated with eating and swallowing was reported (56%), with half of all participants experiencing depression (54%). It is hypothesised here that loss of interest and low mood may develop secondary to non-refractory masticatory dysfunction, as eating and swallowing may become associated with negative outcomes (e.g.: pain, fatigue, choking experiences). The loss of interest in eating may also be associated with the reported high rates of eating less, eating smaller meals, and unintentional weight changes, thus highlighting the potential implications of this issue for overall systemic health. However, due to the confines of the chosen study design, it was unclear here whether this affective was caused by or simply correlated with eating and swallowing problems, and therefore, it is suggested that future research utilises validated questionnaires of affective symptoms to explore this relationship further.

Beyond the potential physical reasons for a loss of interest in eating, it is suggested that social factors may also influence patient behaviour and emotional well-being. Participants here reported nervousness, embarrassment, and worry related to potential exposure of their eating and swallowing difficulties (see Sections 5.2. and 6.2.). These findings resemble those previously published on patients living with “invisible illnesses”. To expand, patients presenting with conditions which cause no overt physical disability often report uncertainty about whether to disclose their issues to those in their personal or occupational networks(304). This uncertainty relates to the perceived or actual threat of unfair stigmatisation associated with the disclosure of a disability(305). It is hypothesised here that the loss of interest in eating among patients with TMDs may also be associated with anxiety about exposing their hidden disability, and potentially introducing the risk of discrimination and isolation. Trends in the data suggest that patients who present with conditions affecting the internal TMJ structure, with no observable external manifestation of dysfunction, report the highest levels of anxiety regarding exposure (e.g.: arthralgia: 62%; DDWOR: 57%) (see Section 5.2.). This is in comparison to no participants with RA reporting this experience (see Section 5.2.), potentially due to:

1. The public awareness of RA and the support of charitable organisations advocating for these patients;
2. The overall systemic nature and frequent visibility of body-wide joint destruction, and
3. The associated overt functional impairments and frequent reliance on external supports (e.g.: mobility aids).

These factors may combine to increase public awareness and acceptance of conditions such as RA, as compared to TMDs, with potential resultant positive impact on emotional well-being. It is hypothesised that the lack of available clinical supports for these patients may contribute to impaired physical functioning and HRQOL, and that, if provided, early intervention may reduce the risk of negative reinforcement, physical discomfort and dysfunction, and impact on well-being. Therefore, findings here may be used to inform the future research and development of clinical management structures for adults with TMDs and associated eating and swallowing problems.

11.3. The Management of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

It was hypothesised here that limited clinical management would be currently available for patients with TMDs and eating and swallowing problems due to the lack of research on this condition, awareness of its existence, and available management resources to use with this group. This research generated new findings on care provision in this field, as will now be discussed.

The Assessment of Eating and Swallowing Problems in Adults with TMDs

Firstly, as noted, minimal research has been conducted on eating and swallowing problems in adults with TMDs, which may impact negatively on clinician awareness of the existence of these issues and understanding of their nature. It was hypothesised here that this may lead to under-identification of these problems in clinical practice. Support for this hypothesis was provided by the 44% of surveyed professionals who considered these problems to be insignificant, and the 77.5% who do not currently assess for its presence, with qualitative comments also supporting this trend (e.g.: Participant 1: "*first time I had heard of an association between TMD and OD* [oropharyngeal dysphagia]"; and Participant 28: "*This is a topic that we know little about even as specialist* [sic].") (see Sections 3.2. and 9.2.). This potentially indicates the need for greater research on these issues in order to provide appropriate guidance for practicing clinicians in the future.

As noted, some participants reported scepticism regarding the significance of, and need to clinically assess for, TMD-related eating and swallowing problems (see Sections 3.2. and 9.2.). Although eating and swallowing difficulties in this cohort appear to primarily affect the oral phase, without routine implications for airway protection or respiratory status, as in other prioritised cohorts (e.g.: patients with progressive neurological conditions or post-extubation dysphagia), it may be beneficial to consider the potential healthcare and economic ramifications of clinically investigating such issues within routine practice. It has been previously documented that this cohort demonstrate disproportionally high levels of reliance on a range of direct healthcare services (267). In addition, patients in this research reported that having professionals validate and investigate their eating and swallowing problems was a key priority in deriving satisfaction from clinical interactions (see Sections 5.3. and 6.3.). It is therefore hypothesised that patients' high level of reliance on return and emergency clinical visits, and dissatisfaction with current

assessment, may reduce if professionals are trained to: routinely screen for eating and swallowing problems in this cohort; implement interventions in non-complex cases (e.g.: ROM exercises, masticatory muscle massage); and appropriately refer patients onto specialist services in complex cases (e.g.: dieticians in the case of unintentional weight changes). As such, it is suggested here that advocating for routine screening for eating and swallowing difficulties within this under-serviced population may align investigations conducted with patient priorities, improve patient satisfaction with care delivered, and reduce reliance on return clinical visits, thus improving efficiency of care delivery and direct healthcare spending, with overall potential economic and societal benefits.

However, while remaining cognizant of this recommendation, limitations to the implementation of such routine screening do currently exist. For example, this research hypothesised that if clinicians do assess for these problems in adults with TMDs, they must use non-specific tools as there are no available dedicated methods for this group. In the systematic reviews, researchers from primary studies typically employed assessments which were not designed to detect eating and swallowing problems and which may not be suitable for use with these patients, due to the limited resources in this area. It is hypothesised here that these reports subsequently influenced the behaviour of practicing clinicians, as they reported use of assessment protocols which resemble available research templates, and 79% were reluctant to deviate from these systems. In addition, it was noted in the literature review that dynamic tools such as VFSS had not been commonly used within previous research, with these findings mirrored in the findings of the professional surveys here. Although it was initially suggested that the future use of such tools may improve our understanding of eating and swallowing difficulties, in light of the high prevalence and centrality of oral preparatory difficulties to the overall eating and swallowing problems experienced by this cohort, it is therefore suggested that future research prioritises the development of cohort-specific assessment tools of specific oral skills for both clinical and research use which will best support clinicians in their future evaluation of these patients.

In response to this suggestion, a trans-disciplinary structured interview tool, the TEDSS, was developed which can be used to identify the presence and investigate the nature of eating and swallowing problems in adults with TMDs, to draft tentative management goals, and to examine the need for onward referral to specialist clinicians (e.g.: the SLT or dietitian) (see Section 5.1.). Furthermore, an assessment protocol incorporating both subjective tools and IROMs were also developed here which can be used by MDT clinicians with this patient group to assess the presence, nature, and impact of eating and swallowing problems in this cohort. It is hypothesised that the development, dissemination, and clinical implementation of these protocols may improve awareness of these problems in adults with TMDs, facilitate assessment across a range of contexts, and improve patient experience of assessment, satisfaction with overall care, and recovery via the early identification of difficulties.

In addition to the tools specifically developed here, other practical recommendations for clinical assessment which emerged from this research included:

1. The use of varied foodstuffs within mealtime observation assessments, to identify patient strengths, areas of need, and tolerance of a range of textures and consistencies based on naturalistic performance, due to the large number of participants who could not complete the TOMASS protocol;
2. Assessment of oral health, due to the common experience of reduced and painful mouth opening which may reduce individuals' ability to complete hygiene routines, resulting in increased risk of xerostomia; and
3. Collaboration with dieticians to assess if patients who consume modified diets and/or experience unintentional weight changes are adequately meeting their nutritional and hydration requirements to maintain systemic health and well-being.

The Treatment of Eating and Swallowing Problems in Adults with TMDs

As limited information currently exists on the presence, nature, or assessment of eating and swallowing problems in adults with TMDs, it was hypothesised here that the treatment of these problems would also be uncommon. This research found that although up to 100% of surveyed professionals perceive improvements in chewing and oral intake to be important clinical outcomes, up to two thirds do not typically provide intervention to remediate eating and swallowing difficulties, thus suggesting that the lack of available treatment options in this field constrain clinical practice (see Sections 3.2. and 9.2.). This research also found that when clinicians do provide such intervention, half are dissatisfied with available treatment methods (see Sections 3.2. and 9.2.). Aside from diet modifications, clinicians reported reliance on methods which were not designed to remediate eating and swallowing problems. For example, up to 38% of clinicians reported use of occlusal appliances, while 17% used surgery, neither of which are specifically developed to improve eating or swallowing in adults with TMDs, and which therefore may not facilitate recovery. These findings suggest that future research should be conducted to develop specific interventions for use with this group in order to support both clinicians and patients alike.

It is hypothesised that the lack of available treatments for clinicians to use with this group may cause patients themselves to seek out additional interventions for eating and swallowing problems. Qualitative comments indicated that patients prioritise finding a "*cure*" [Participant 58], learning about "*rehab options at acute and subacute stages*" [Participant 3], and "*where and how to get help fast*" [Participant 92] (see Section 6.2.), which may be associated with their reports of accessing a range of complimentary interventions for these problems (see Section 5.2.). Yet these methods were also not designed for treatment of these issues and often lack evidence-based support. When these findings are considered as a whole, the clinical and personal use of multiple techniques which are not designed to address eating and swallowing problems potentially dilutes opportunities for recovery, and these techniques may also interact negatively with one another, thus introducing further ethical, medical, psychological, and economic risks. As such, the development of evidence-based population-specific treatments may support clinicians in their provision of patient-centred care, with subsequent potential improvements in patient recovery and well-being, and secondary benefits for logistical and economic aspects of service delivery.

Across this research, diet modifications were reported to be the only available population-specific intervention technique. Yet, although up to 41% of professionals reported advising patients to eat softer diets to accommodate masticatory issues, twice this number of patients reported consuming texture modified diets (81%) (see Sections 5.2. and 6.2.). This suggests that patients with TMDs may independently consume modified diets in the absence of clinical advice. As diet is a key influencing factor in systemic health and activity, and in light of the participants here who consumed modified diets and experienced unintentional weight changes, future research into the potential for modified diets to contribute to and perpetuate these changes is required in order to understand the potential for developing secondary systemic problems. In addition to the these hypothesised physical effects, consuming a texture modified diet may also be associated with psychosocial implications(302), as patients here reported concerns about living well despite consuming modified diets (e.g.: Participant 100: "*How will I cope with this diet?"* and Participant 112: "*Will I ever be able to eat?*"). It is therefore suggested that the research and design of new education and service delivery structures to support both patients and professionals in this area is warranted. For example, there may be the potential for clinicians such as SLTs and dietitians to collaboratively develop trans-disciplinary training on appropriate diet modifications and weight management, which, if successful, may inform future care provision to this group. In addition, it is suggested that the direct involvement of SLTs and dietitians in the management of patients with TMDs and non-refractory eating and swallowing concerns may also positively impact clinical outcomes and patient recovery.

In addition to diet modifications, practical suggestions for current clinical intervention also include:

1. The use of masticatory muscle massage, stretching, and relaxation techniques in order to address and reduce primary muscle spasm in patients with masticatory muscle disorders (e.g.: MFP), or secondary muscular issues in those experiencing intra-articular difficulties (e.g.: DDWOR);
2. The trialling of ROM, strength, and endurance exercises with patients who present with intra-articular issues, and who are experiencing muscular spasm, atrophy, or de-conditioning post-operatively;
3. Collaboration with occupational therapists to advise on adapted cutlery in cases of severely reduced mandibular ROM;
4. Close liaison with orofacial pain specialists and OMFS to determine the true functional impact of analgesia/surgical intervention via therapeutic trials of a range of diet consistencies, and monitoring or their tolerance, pain and fatigue levels, and overall satisfaction ratings; and
5. Provision of appropriate patient education on the prevalence, nature, and management of TMD-related eating and swallowing difficulties based on contemporaneous evidence-based research.

The Overall Management of Eating and Swallowing Problems in Adults with TMDs

It was hypothesised that secondary to the difficulties outlined above, both clinicians and patients may be dissatisfied with overall care provision in this field. Findings of the research here support this hypothesis, with clinicians emphasising dissatisfaction with current management, and their need for greater guidance in this field (e.g.: "*I feel this area is very poorly managed*" [Participant 5]; "*More guidance is required*" [Participant 6] (see Section 3.2.)), while patients reported that they often felt isolated during TMD management and that they prioritised a greater focus on eating and swallowing problems (e.g.: "*This is the first time anyone has made the connection between my jaw problem and my swallowing problem - it's like a weight has been lifted*" [Participant 117]; "*I want to know everything… today is the first time I have been listened to and understood*" [Participant 85] (see Section 6.2.)). Therefore, this research may have the potential to inform future developments in the provision of care to this patient group.

In addition to the contributing factors outlined in previous sections, professionals also reported that clinical isolation is influential in their dissatisfaction with care provision to this group. As discussed, previous TMD research has documented the lack of routine interactions between clinicians, and the impact which this may have on knowledge sharing and the provision of cohesive care(235). The current research documented that up to 35% of clinicians surveyed who provide care to patients with TMDs currently work in isolation, without opportunities for peer learning, inter-disciplinary reflection, or knowledge sharing (see Sections 3.2. and 9.2.). Clinicians reported that this isolation reduces their confidence in collaborating with specialist inter-disciplinary colleagues in order to address eating and swallowing concerns in patients with TMDs (e.g.: Participant 19: "*Would be nice to get uptodate guidelines*"; Participant 20: "*unsure who to refer to in this situation*") (see Section 3.2.)). This was reflected in the low numbers of surveyed professionals who currently liaise with SLTs or dietitians when managing these patients, in contrast to 38% who reported a need for future additional support from these specialists (see Sections 3.2. and 9.2.). As such, future research to initiate collaborations between practitioners typically involved in TMD care provision and clinicians skilled in the management of eating and swallowing problems is required in order to support service delivery to these patients.

In this research, both patients and professionals reported parallel needs for contemporaneous and accessible guidance on the presentation and management of TMD-related eating and swallowing problems. Therefore, in the interim before research is conducted into the development of interventions and MDT structures in this field, an educational resource was designed and piloted here. In line with patient-reported priorities, the key themes addressed in this tool were the epidemiology and nature of TMD-related eating and swallowing problems and currently available trans-disciplinary management options (see Section 6.2.). In recognition of the limited available information on direct treatments for these issues, details regarding the generic treatments which are most commonly used in TMD practice were provided, with discussion of how these interventions may interact with and impact on eating and swallowing problems. In addition, with consideration of the frequent use of diet modifications and the potential for unintentional weight

changes in this group, this tool also described different levels of both diet, and indeed, mealtime modifications to address these issues. This resource will be further refined in subsequent research using patient-reported data collected here, in order to increase the salience of information provided and to support clinicians in their delivery of care to these patients.

11.4. Overall Limitations of Research

Overall limitations of this research include: the demographic profile of patients recruited during the prospective studies, potential confounding factors which were not accounted for in assessment, and the limited number of clinicians who participated in the surveys of professional perspectives. To expand, patients recruited here were sampled on their presentation for treatment to national specialist centres of tertiary care. Therefore, samples may be inappropriately skewed due to patients experiencing severe non-refractory TMDs not remediated by routine primary or secondary care, potentially introducing recruitment, detection, or recall bias which negatively impacts on sample representativeness. As such, it is advised that future research recruits both treatment-seeking patients presenting to primary and secondary specialist and non-specialist care facilities, and non-treatment seeking individuals living with TMDs within the general community. In addition, possible confounding factors such as the use of analgesia or psychotropic medications for pain management were not investigated in this research, despite their potential to impact on pain levels and functioning in some patients. Therefore, factors such as these may have impacted on performance in assessment, and influenced results inappropriately. As such, it is advised that future research investigates such factors to ensure accurate representation of these symptom profiles. Finally, limited numbers of clinicians were recruited for participation in the surveys of professional perspectives. This may have resulted in the recruitment of professionals with a special interest in this field or in participation in academic research in general, with data generated from these small samples being potentially unrepresentative of overall views of the target groups. As such, future research should use targeted recruitment strategies to attract a more diverse range and greater number of clinicians to ensure representativeness, reliability, and validity of findings.

11.5. Recommendations for Future Research

To begin, findings of this research suggest that patients with inflammatory and non-inflammatory TMD issues may present with different profiles of eating and swallowing problems. Therefore, future research investigating these symptom profiles in representative samples is advised which may subsequently inform the need to research and design targeted population-specific intervention strategies for use with these groups. In addition, validation of the new structured interview tool and assessment protocol is recommended to determine if they are sufficiently valid and reliable for future clinical use. It is advised that these tools are used both with individuals with TMDs who seek treatment in primary and secondary care centres and those living in the

community who do not seek TMD treatment in order to ensure that representative groups are sampled.

Furthermore, few professionals were recruited for the clinician surveys here (see Sections 3.2. and 9.2.), with most participants recruited from a national conference using paper-based surveys. This is in comparison to the limited number of clinicians recruited via the use of online surveys. Therefore, it is suggested that future work in this area should use similar targeted recruitment strategies in order to maximise participation and representativeness. Finally, findings here suggested that patients prioritise the receipt of more information from clinicians on eating and swallowing difficulties, with 99% reporting that receiving this information would be beneficial to their overall recovery (see Section 6.2.). Therefore, further refinement, integration of patient data collected here, and gathering of additional feedback from representative patient samples on the new educational resource is recommended to ensure information salience.

11.6. Recommendations for Future Developments in Clinical Practice

Although the TEDSS (see Section 5.1.) and the trans-disciplinary assessment protocol (see Section 6.1.) require further validation and refinement to determine their psychometric properties, it is suggested that may also be used in clinical practice currently to guide clinicians in their investigation and profiling of eating and swallowing problems in adults with TMDs, while remaining cognizant of the current limitations of these tools. When these tools are refined, it is recommended that they are used during typical TMD management in order to improve the identification and management of eating and swallowing problems in this group. In addition, although future research is planned to improve the content and format of the educational tool developed here, the pilot version is also suitable for dissemination now, with clinicians in the sampling locations of this research currently providing patients with copies of this resource. As above, it is advised that on publication of the updated resource, this tool is disseminated to individuals with TMDs in order to share information and to promote awareness and management of these eating and swallowing problems.

Finally, it is also advised that clinicians with specialist skills in the management of eating and swallowing problems (e.g.: the SLT and dietitian) are integrated into TMD MDT structures in order to contribute to the management of these difficulties. It is hypothesised that integration may be facilitated in a number of ways, including:

1. A direct role for these specialists in which they provide management for eating and swallowing problems within routine clinical contexts;
2. The provision of basic education on the management of eating and swallowing problems to clinicians typically involved in TMD management, in conjunction with direct involvement of specialists in non-refractory cases; or
3. An indirect role for these specialists where in-depth clinical education on the management of these issues is provided to professionals typically involved in TMD management.

11.7. Summary of Research Output

Throughout this research, 4 studies were published in international academic journals, with journal themes ranging from OMFS, to dentistry, and dysphagia, demonstrating the MDT applicability of findings (see Appendix 36). In addition, findings of these studies were also shared via both oral and poster presentations at national and international academic conferences, thus creating opportunities for improved clinical and academic awareness of these difficulties, and fostering relationships with international MDT expert clinicians and academics.

11.8. Overall Conclusions of Research

This research highlighted that eating and swallowing problems may develop secondary to masticatory impairments, and that these difficulties are prevalent among adults presenting with TMDs, despite limited previous research on this topic. Findings also indicated that patients presenting with inflammatory and non-inflammatory TMDs may experience different subsets of eating and swallowing problems, thus suggesting the need to develop individualised cohort-specific management techniques for these groups. In addition, this research found that regardless of symptom profiles, TMD-related eating and swallowing difficulties impact on physical and occupational functioning, participation in personally relevant ADLs, emotional well-being, and HRQOL.

A snapshot of the current management of eating and swallowing problems in adults with TMDs was also provided here. Due to the complex presentation of these patients, and the lack of available research on, or resources for use with this group, clinical management is currently limited, and both professionals and patients report negative perceptions of typical care provision. In order to support clinicians working in this field, a new cohort-specific structured interview tool and assessment protocol were developed here which are suitable for immediate clinical use, although future validation is recommended. In addition, in response to patients reporting the need for more information on TMD-related eating and swallowing problems, a new educational resource was developed which provides accessible information on these issues and their management, with the view to improve knowledge sharing on and awareness of these difficulties. The avenues identified here for improvements in the management of eating and swallowing problems in adults with TMDs aim to promote continued research in this field beyond this initial catalyst, in order to ultimately inform the future delivery of patient-centred care and to improve the patient's journey to wellness and recovery.

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Appendix 1: Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Irish Dental Professionals' Perspectives on Management

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

26 July 2017

Academic Year: 2016/17

Applicant: MT9 Órla Gilheaney

Project title: A Survey of Irish Dental Professionals' Perspectives regarding the Evaluation and Management of Oropharyngeal Dysphagia associated with Temporomandibular Disorders

Dear Orla,

Your changes to the previously approved research project above were considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin and have been approved in full. I wish you the very best in your research activities.

Professor John Saeed

Chair, Research Ethics Committee

School of Linguistic, Speech and Communication Sciences

Trinity College Dublin

Appendix 2: Participant Information Leaflet: Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Irish Dental Professionals' Perspectives on Management

Title of Study:

Oral Stage Dysphagia and Temporomandibular Disorders: Irish Dental Professionals' Perspectives on Management.

Introduction:

I am Órla Gilheaney, a Ph.D. student studying in the Department of Clinical Speech and Language Studies, Trinity College Dublin. I am conducting research on TMDs. I am surveying the perspectives of dental professionals working in Ireland with patients presenting with eating and swallowing problems related to difficulties with the temporomandibular joint. I would like to invite you to take part in this research.

Procedures:

You are eligible to take part in this survey if you are a dental professional working in Ireland with patients experiencing temporomandibular disorders. This survey will take a maximum of five minutes to complete. No identifying information is sought. When the survey is completed you can place it in the sealed box provided.

Benefits:

This study potentially can provide some information about the perspectives of dental professionals working in Ireland with patients experiencing eating and swallowing difficulties caused by jaw joint problems. This study may also be the first step in developing standardised management approaches for these difficulties.

Risks:

By taking part in this research study, there is no further personal risk than if you were not to participate.

Confidentiality:

All information collected will be anonymous. No identifying information will be collected. This survey has been approved by the Research Ethics Committee of the School of Linguistics, Speech, and Communication Sciences, Trinity College Dublin, Ireland.

Reimbursements:

No monetary reimbursement will be provided for participation in this survey.

Further Information:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from the primary investigator, Órla Gilheaney, who can be contacted at the details below.

Name: Órla Gilheaney.
Address: 7-9 South Leinster Street, Dublin 2, Ireland.
Phone number: +353 876213244.
Email address: Gilheano@tcd.ie.

Appendix 3: Survey: Eating and Swallowing Problems in Adults with Temporomandibular Disorders: Irish Dental Professionals' Perspectives on Management

Question number	Question	Answer Options
1	In what specialist area of dentistry do you primarily work?	1. General Dentistry 2. Prosthodontics 3. Oral Medicine 4. Oral and Maxillofacial Surgery 5. Orofacial Pain 6. Oral Surgery 7. Other (please specify)
2	In what type of facility do you work?	1. Teaching hospital 2. Non-teaching hospital 3. Community care 4. Private practice 5. Other
3	How many years of clinical experience do you have?	1. None 2. <1 year 3. 1-5 years 4. 6-10 years 5. 11-15 years 6. >15 years
4	How significant do you think dysphagia is in TMD patients?	1. Not at all significant 2. Slightly significant 3. Significant 4. Fairly significant 5. Very significant
5	Do you agree/disagree that the following outcomes are important when managing patients experiencing dysphagia and TMDs? 1. Improvement in swallowing 2. Improvement in chewing 3. Improvement in oral intake 4. Improvement in range of motion 5. Reduction of pain 6. Reduction of fatigue 7. Improvement in quality of life 8. Occlusal changes 9. Reduction of parafunctional habits (e.g.: bruxism) 10. Patient education 11. None of the above	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
6	Do you have clinical experience in the management of patients with dysphagia and TMD? (If no, please proceed to the end of the survey).	1. Yes 2. No
7	Do you agree/disagree with these statements? 1. I routinely assess for dysphagia in people with TMD 2. I use a specific assessment protocol with people with TMD and dysphagia 3. This assessment protocol differs based on the presence/absence of dysphagia 4. If dysphagia is suspected in a TMD patient I will refer the patient for videofluoroscopy 5. If dysphagia is suspected in a TMD patient I will refer the patient to appropriate team members	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
8	What assessment methods do you routinely use for patients with TMD who report dysphagia?	1. I do not routinely assess for this 2. Subjective clinical examination 3. Dental examination 4. Self-report questionnaires 5. RDC/TMD protocol 6. Objective imaging assessment 7. Other
9	What treatment methods do you routinely use for patients with TMD who report dysphagia?	1. I do not routinely treat this 2. Compensatory techniques (e.g.: diet modifications) 3. Non-swallow exercise (e.g.: chewing exercises) 4. Swallow exercises (e.g.: effortful swallow) 5. Occlusal appliances 6. Surgery 7. Orthodontics 8. Relaxation techniques 9. Thermal packs

		10. Medications 11. Patient education and counselling 12. Other
10	Which professionals do you typically liaise with when managing patients with dysphagia and TMDs?	1. Dentist 2. Gastroenterologist 3. Medical physician 4. Neurologist 5. Surgeon 6. Nurse 7. Dietitian/ Clinical nutritionist 8. Speech and language therapist 9. Occupational therapist 10. Physiotherapist 11. Pharmacist 12. Engineer 13. Radiologist 14. Otolaryngologist 15. Other
11	Which professionals that you currently do not work with would you like to liaise with when managing these patients?	1. Dentist 2. Gastroenterologist 3. Medical physician 4. Neurologist 5. Surgeon 6. Nurse 7. Dietitian/ Clinical nutritionist 8. Speech and language therapist 9. Occupational therapist 10. Physiotherapist 11. Pharmacist 12. Engineer 13. Radiologist 14. Otolaryngologist 15. Other
12	Do you agree/disagree with these statements? 1. I am satisfied with available assessment methods used with TMD patients experiencing dysphagia 2. I am satisfied with available treatment methods used with TMD patients experiencing dysphagia 3. I am satisfied with the overall quality of care typically provided to TMD patients experiencing dysphagia	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
13	Do you have any further comments that you would like to share on this topic?	

Appendix 4: Associated Publication: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

ACTA ODONTOLOGICA SCANDINAVICA, 2018
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REVIEW ARTICLE

Check for updates

The prevalence of oral stage dysphagia in adults presenting with temporomandibular disorders: a systematic review and meta-analysis

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ABSTRACT

Objective: Temporomandibular disorders (TMDs) are the most commonly experienced non-dental orofacial pain disorders, with pain and dysfunction potentially resulting in oral stage dysphagia (OD). However, limited research has been conducted on this condition, with potential negative effects on clinical practice. Therefore, the aim of this study was to determine the prevalence of OD in adults presenting with TMDs, diagnosed as per the Research Diagnostic Criteria for Temporomandibular Disorders or the Diagnostic Criteria for Temporomandibular Disorders protocols.

Material and methods: A systematic review of the literature was completed. Nine electronic databases were searched from inception to January 2017, with no date/language restriction applied. Grey literature, conference proceedings, and reference lists were also searched. Studies presenting original data regarding OD prevalence in adults presenting with TMDs were included if they investigated impaired swallowing, mastication, masticatory pain or fatigue, or weight loss. Study eligibility and quality were assessed by two independent reviewers. Methodological quality was assessed using the Down's and Black tool.

Results and conclusions: This search yielded 20 eligible studies. Swallowing itself was impaired in only 9.3% of patients with TMDs. A range of additional OD signs and symptoms were also commonly reported (e.g. masticatory pain (87.4%) and fatigue (62%)). Study limitations included the small number of studies which were eligible for inclusion. As signs and symptoms of OD are frequently reported by patients with TMDs, psychometrically robust prospective research is warranted to determine current and optimal management of this condition.

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KEYWORDS
Dysphagia; temporomandibular joint; temporomandibular joint disorder; prevalence

Introduction

Temporomandibular disorders (TMDs) are a cluster of conditions caused by alterations in the structure and/or function of the temporomandibular joint (TMJ), the wider masticatory muscle system, and/or osseous components, which are commonly characterised by heterogeneous signs and symptoms [1–8]. TMDs are the most frequent orofacial pain disorders of non-dental origin, and are also reported to be the second most common musculoskeletal and neuromuscular disorder after lower back pain, with up to a striking 93% of the general population showing at least one TMD sign or symptom on examination, and 10–20% of these individuals seeking treatment [9–17]. Although the clinical presentation of TMDs are frequently heterogeneous [1], commonly experienced signs and symptoms include: pain, dysfunction, and fatigue of the TMJ and muscles of mastication, limitations of mandibular movement and mouth opening, impaired oral transit, and the potential for unintentional weight loss [2,18–21]. These functional difficulties have the potential to combine to impair typical eating, drinking, and swallowing, causing oral stage dysphagia (OD), which may subsequently impact on quality of life (QOL) [22–24].

Despite the potential for adults who present with TMDs to develop OD which may impact upon both functioning and well-being, there has been limited epidemiological research into this condition. Also, various methodological limitations within the available evidence render it difficult to determine the true prevalence and nature of TMD-related OD [18]. These issues include: (1) diversity in the definition of key terms such as what constitutes a diagnosis of OD; (2) reported historical use of unspecified subjective assessments which may not have adequate sensitivity to detect OD; (3) increasing use of the Research Diagnostic Criteria for Temporomandibular Disorders [25] and recently updated Diagnostic Criteria for Temporomandibular Disorders [22] protocols in clinical and academic fields, which although standardised, address TMD-related OD in a brief manner; (4) lack of reporting of specific TMD diagnoses of participants; (5) and lack of adequate description of and adjustment for confounding factors. As such, a valid and reliable description of the epidemiology of TMD-related OD is required in order

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to describe the nature and significance of this condition, and to provide rationale for improvements in its typical identification and management practices. Therefore, the aim of this study was to conduct a systematic review and meta-analysis of the epidemiology of the following signs and symptoms of OD in adults presenting with TMDs: impaired swallowing and mastication, masticatory pain and fatigue, and unintentional weight loss.

Material and methods

This systematic review was conducted in accordance with The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [26] and MOOSE Guidelines for Meta-Analyses and Systematic Reviews of Observational Studies [27]. The protocol was prospectively published on the University of York Centre for Reviews and Dissemination Prospero database (Registration number: CRD42016050846) [28]. For the purpose of this study, the definition of OD was as follows: sensory and/or motor difficulties in the movement of a liquid or solid bolus from the oral cavity to the esophagus, inclusive of concomitant emotional, cognitive, and functional difficulties [29]. Originally, the aim of this study was to study the prevalence of broad oropharyngeal dysphagia [28]. However, on further reading and reflection, the focus was narrowed to purely oral stage dysphagia-related difficulties, as these are most relevant to disorders of the structure or function of the TMJ complex.

Eligibility criteria

All published/unpublished records presenting original prevalence figures were eligible for inclusion, with no language, geographic, or date limitations applied. Case reports were excluded due to criticisms regarding their typically low levels of evidence. Prevalence figures were sought regarding humans aged 18 years and over presenting with oral and/or oral preparatory signs/symptoms of OD related to TMDs, as diagnosed using the RDC/TMD [25] or the DC/TMD [22]. The RDCTMD was the most widely used TMD diagnostic protocol since its publication in 1992 until the 2014 publication of the DC/TMD [30]. This system facilitates the characterisation of both the physical and emotional difficulties associated with TMDs and the protocol was based on the biopsychosocial model of pain. The RDC/TMD protocol includes a comprehensive Axis I physical assessment and Axis II examination of psychosocial functioning and pain-related disability. The more recent DC/TMD system [22] is a dual axis assessment tool which provides evidence-based criteria for clinicians to apply when assessing patients and which facilitates trans-disciplinary communication. This system present a more comprehensive and contemporaneous selection of assessment tools than the RDC/TMD for both the brief screening for and in-depth examination of a spectrum of simple and complex TMDs [22]. No restrictions were applied regarding sex, race, disease duration, severity, age-of-onset, or recruitment location. Individuals were not eligible for inclusion if they had a history of conditions which may result in mandibular or orofacial dysfunction (e.g. head and/or neck cancer, comorbid/congenital conditions of the maxillofacial area, or orthopaedic or neurological trauma to the orofacial region).

Outcomes of interest

Outcomes of interest in this systematic review included:

1. Impaired deglutition and mastication as reported subjectively and/or detected objectively via clinical examination, interviews, questionnaires, and/or imaging techniques;
2. Masticatory pain as reported in interviews, questionnaires, or as rated using subjective scales;
3. Masticatory fatigue as reported via interviews, questionnaires, subjective scales, or detected using clinical or electromyographic (EMG) assessment; and
4. Unintentional weight loss related to OD as reported by the patient or detected via clinical examinations.

Originally, investigators also aimed to research the prevalence of the consumption of texture modified diets by the cohort of interest within this study [28]. However, in order to provide clarity via the separation of epidemiological and management issues, and to afford sufficient attention to these parameters, this estimate will be separately presented in a subsequent report.

Data sources

A sensitive search strategy incorporating filters, key-text and Medical Subject Headings was systematically employed across databases by two independent reviewers (Appendix 1). The databases searched from inception to January 2017 included: EMBASE, PubMed, CINAHL, Web of Science, Elsevier Scopus, Science Direct, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. All search results were subsequently exported to the Zotero bibliographic system (www.zotero.org). Subsequent to duplicate deletion, two authors independently screened titles/abstracts in order to exclude obviously irrelevant papers. A third author was available to independently mediate disputes, if required. The senior author also conducted hand-searches of annual scientific meeting proceedings of the International Association for Dental Research (published in the *Journal of Dental Research*) and the European Society for Swallowing Disorders (published in *Dysphagia*). Hand-searches of the reference lists of studies ultimately included in the systematic review and meta-analysis were also conducted, with one eligible study identified [31]. Subsequent to the completion of the above systematic searches, the senior author also further searched the Google Scholar database in an effort to identify records not indexed in the initially searched databases, resulting in 13 additional eligible studies [32–44]. Eligible records which were included in the systematic review will be discussed in subsequent sections.

Data extraction process and data items

A previously piloted electronic form [45] was used in data extraction by six independent reviewers. Data were extracted regarding study design, setting, and location, participant demographics, outcome measurement and data sources, prevalence and statistical analysis, among other parameters. Reviewers reached 100% consensus regarding data extracted. One author not involved in data extraction was available to mediate disputes if they occurred. Missing/unclear data was addressed via the senior author contacting primary authors of studies published within the previous 10 years. The figure of 10 years was chosen to accommodate the usual 5-year research retention period and to circumvent exclusion of records which were published more than 5 years ago, but primary authors had retained records past this period for retrospective analysis. Records were excluded following no response to two contact attempts.

Assessment of methodological quality

Two independent reviewers assessed the methodological quality of included studies utilising a previously piloted [45] modified Down's and Black Tool [46] which omitted criteria deemed irrelevant to the aims of this study (e.g. intervention, adverse events, blinding and randomisation) (Appendix 2). Primary studies which recruited a comparison group were marked out of 18 points, while those without comparison groups were rated out of 16 points, as 2 criteria pertained to the recruitment of a control group.

Summary measures and synthesis of results

Included studies were first described descriptively, with subsequent statistical analysis. Fixed and random effects meta-analyses of prevalence estimates were carried out utilising the Microsoft Excel package [47] and the MedCalc system [48]. Prevalence figures were presented using 95% confidence intervals, with forest plots constructed for all estimates.

Results

Study identification

Systematic searches yielded 10,248 results, as shown in the PRISMA figure (Figure 1). Following the exclusion of 4245 duplicates and 5381 records based on their titles, abstract,

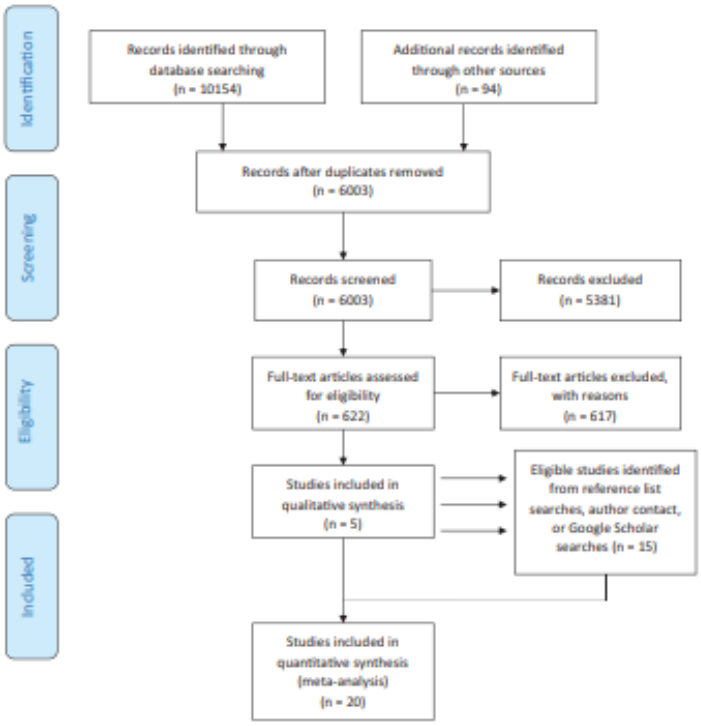

Figure 1. PRISMA diagram.

and/or keywords, two independent reviewers examined 622 full-text records, with a third author available to independently mediate disputes, if required. At this stage, 617 of these full-text records were excluded. Supplementary Google Scholar searches identified 13 further eligible studies [32–44]. An additional eligible article was identified from reference list searches [31] and one further article was identified via author contact [49].

Missing/inconsistent/insufficient data were addressed by the senior author contacting primary authors of studies published within the last 10 years, in order to allow for both the typical 5-year retention period and to also avoid forcible exclusion of studies if they were dated beyond this period yet records were retained for post-hoc analysis. Records were excluded in the case of two unanswered contact attempts. In total, during both foundational and supplementary Google searches, 291 contact attempts were made regarding 155 potentially eligible records. For 117 of these studies, missing data were sought, while 38 communications related to article access. Contact led to the confirmation of 12 eligible studies, the exclusion of 3 studies excluded due to inappropriate participants, 24 excluded due to insufficient data, 98 excluded due to no response, 5 excluded due to inappropriate research objectives, 3 due to use of inappropriate outcome measurement tools, and 10 studies excluded due to inability to access records. Ultimately, 20 studies satisfied the inclusion criteria, had data extracted, and were included in analysis.

Study characteristics

Included study characteristics are described in Table 1.

Half of included records ($n = 10$) were case-control studies (50%), while 20% ($n = 4$) were descriptive observational studies, 3 (15%) were RCTs, 10% ($n = 2$) were cross-sectional studies, and 5% ($n = 1$) were prospective cohort studies. Study locations included Europe ($n = 7$/35%), South America ($n = 5$/25%), North America ($n = 3$/15%), Asia (5%/$n = 1$), Australia (5%/$n = 1$), and Israel (5%/$n = 1$). A small cohort did not specify study location ($n = 2$/10%) [36,50]. Study settings varied, with the majority conducted in university clinics ($n = 10$/50%), university teaching hospitals ($n = 3$/15%), and dual study settings ($n = 3$/15%). It was unclear what the settings of two studies were [36,50].

Sources of assessment data varied, with 19 studies (95%) utilising the RDC/TMD [25] and 1 study (5%) [51] employing the DC/TMD system [22]. Objective assessments were employed in six studies (30%) (Table 1). Assessments of mastication were used in eight studies (40%). Visual analogue scales were used in six studies (30%) to gather patient-reported data. Subjective questionnaires were used in 16 studies (80%), with a range of 24 such tools being employed.

Description of participant demographics

Data regarding 1581 patients were included, with the pooled age range of available and eligible participant data being 18–88 years of age. A small cohort of included studies did not provide mean ages of eligible participants ($n = 4$/20%), while 60% ($n = 12$) of eligible studies did not provide details regarding age ranges. A total of 1136 females and 351 males (3.23:1; female: male) were included, while two studies [42,44] did not provide details on gender. The diagnoses with which eligible participants presented are shown in Table 2. The discrepancy between the number of participants recruited ($n = 1581$) and the total number of diagnoses presented below ($n = 1623$) is due to certain studies applying diagnostic criteria to both TMJs, while others classified patients according to the unilateral TMJ which was most impaired.

The most frequently reported diagnoses were myofascial pain disorder (MFP) ($n = 672$/41.2%), Disc displacements (disc displacement with reduction (DDWR): $n = 275$/16.9%; disc displacement without reduction DDWOR: $n = 95$/5.8%), and arthralgia ($n = 190$/11.6%). A large cohort were classified as presenting with dual diagnoses ($n = 229$/14%), with MFP + DD/osteoarthritis (OA) being the most frequent ($n = 91$/5.6%). Two studies provided unclear diagnoses, classifying participants as presenting with either DD or OA ($n = 32$) [39], or MFP combined with DDWR or OA ($n = 91$) [42] (Table 2).

Assessment of methodological quality of included studies

Two authors independently reached 100% consensus relating to quality ratings, without disputes. Utilising the Down's and Black tool, studies recruiting a comparison group were awarded an average of 11.3, indicating a mean rating of moderate quality (Table 3).

The items primarily responsible for lower methodological quality ratings were: inadequate/lack of description of whether participants who were prepared to participate were representative of the entire population ($n = 12$/60%); inadequate description of patients who were lost to follow-up ($n = 12$/60%); and inadequate description of the distribution of and adjustment for confounding factors ($n = 10$/50%). Contributing to positive ratings was the judgement that all studies ($n = 20$) clearly described primary aims, hypotheses, and outcomes; 95% ($n = 19$) utilised accurate outcome measurement tools; 95% ($n = 19$) utilised appropriate statistical tests to assess main outcomes; and the characteristics of participants were clearly described in the majority ($n = 17$/85%) of included studies.

Prevalence of investigated outcomes

Based on data extracted from 7 studies ($n = 215$ patients) [32,34,41,49,50,52,53], the prevalence of impaired deglutition was estimated to be 9.3% (95% CI: 2.1–20.86%) (Figure 2).

Impaired mastication was reported in 16 studies ($n = 1064$ patients) [31–37,40,41,43,49–54], with this prevalence estimated to be 52.67% (95% CI: 37.182–67.91%) (Figure 3).

Masticatory pain was reported in six studies ($n = 734$ patients) [31,38,39,42,44,49], with this prevalence estimated to be 87.38% (95% CI: 74–96.39%) (Figure 4).

Table 1. Characteristics of included studies.

Citation/Year/Region/ Setting	Study design	No. of TMD patients studied	Female: male ratio	Mean age (SD) of TMD patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (months)	Relevant outcome measured	Sources of assessment data	Study quality score: Down's and Black checklist
Baker et al., [41]/2015/ Sweden/University clinic	Randomised control trial (RCT)	34	10.3:1	38.9 (± 15 y)	Unclear	49.1 (unclear)	Impaired swallowing: 5.88%; Impaired mastication: 20.58%	RDCTMD, X-ray, magnetic resonance imaging (MRI), IMMPACT questionnaire, visual analogue scale, JFLS-8, Graded Chronic Pain Scale (GCPS), Symptom Checklist-90-Revised (SCL-90R)	15/18
Wanman [43]/2012/ Sweden/University clinic	Case-control	108	5.23:1	40 (±13)	Unclear	Unclear	Impaired mastication: 62.96%	RDC/TMD, subjective questionnaire, endurance tests, visual analog scale	11/18
Mapelli et al., [34]/2016/ Brazil/University clinic	Case-control	30	9:1	30.5 (Unclear)	Unclear	59.2 (7-240)	Impaired mastication: 76.6%	RDC/TMD, ProTMDmulti questionnaire, EMG	13/18
Foteder et al., [35]/2015/ India/University hospital clinic	Cross-sectional	195	5.91:1	34.8 (± 17.2)	Unclear	Unclear	Impaired mastication: 54.32%; Masticatory fatigue: 50.61%	RDC/TMD, patient interviews, case history, OHIP-14	12/18
Abrahamsson [37]/2013/ Sweden/University hospital clinic	Case-control	90	1.37:1	22 (± 7.4)	Unclear	Unclear	Impaired mastication: 75.2%	RDC/TMD, visual analog scale, subjective questionnaire, self-reported masticatory ability, masticatory performance test, dental exam	16/18
Ferreira et al. [32]/2016/ Italy/Specialised private practice facial pain clinic and university hospital clinic	Case-control	12	12:0	37 (±16)	Unclear	39 (unclear)	Impaired swallowing: 0%; Impaired mastication: 41.66%; Masticatory fatigue: 66.6%	RDC/TMD, ProTMDmulti, orofacial myofunctional evaluation with scores (OMES), near infrared spectroscopy	15/18
La Touche et al., [42]/ 2015/Spain/Specialised private practice facial pain clinic and public health centre	Case-control	33	Unclear	Unclear	Unclear	Unclear	Masticatory pain: 96.38%; Masticatory fatigue: 98.79%	RDC/TMD, subjective questionnaire, visual analog scale, Pain Catastrophizing Scale (PCS), provocation chewing test, pressure pain threshold, maximal mouth opening, Neck Disability Index, Headache Impact Test-6	16/18
Dougall et al., [39]/2012/ America/General dental practice	Descriptive observational	185	4.28:1	42.68 (unclear)	Unclear	Unclear	Masticatory pain: 89.72%	RDC/TMD, Characteristic Pain Index (CPI), GCPS, chewing performance test, Medical Outcomes Shortform-36 Status Questionnaire, SCL-90R, Beck Depression Inventory	11/16
Khawaja et al., [50]/ 2015/America/ University clinic	Descriptive observational	94	1.47:1	34.2 (±12.2)	Unclear	Unclear	Impaired mastication: 56.38%	DC/TMD, Oral Behaviours Checklist (OBC), GCPS, CPI, MRI, Patient Health Questionnaire (PHQ), Generalised Anxiety Disorder Scale	11/16
Maffei et al., [51]/2012/ Unclear/Unclear	Descriptive observational	10	1.5:1	Unclear	Unclear	Unclear	Impaired swallowing: 70%; Impaired mastication: 90%	RDC/TMD, VFSS, SLT OD assessment	6/16
De Felicio et al., [52]/ 2012a/Brazil/University clinic	Case-control	30	1:0	30 (±8)	Unclear	Unclear (6-108)	Impaired swallowing: 0%; Impaired mastication: 0%	RDC/TMD, EMG, OMES, ProTMDmulti	12/18
Da Silva et al., [49]/2011/ Brazil/University clinic	Case-control	70	0.84:1	53 (unclear)	Unclear	Unclear	Impaired swallowing: 16.6%; Impaired mastication: 11.1%;	RDC/TMD, salivia flow evaluation, xerostomia questionnaire, dental exam	12/18

(continued)

Table 1. Continued

Citation/Year/Region/ Setting	Study design	No. of TMD patients studied	Female: male ratio	Mean age (SD) of TMD patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (months)	Relevant outcome measured	Sources of assessment data	Study quality score: Down's and Black checklist
							Masticatory pain: 72.2%		
Raphael & Marbach [53]/ 2001/America/ University clinic and general dental practice	RCT	63	1:0	33.7 (±10.9)	Unclear	60 (UNC)	Impaired swallowing: 7.93%; Impaired mastication: 49.2%;	RDC/TMD, SCL-90, clinical exam, self-reports of pain, functional out-come assessment	16/18
Barros et al., [33]/2008/ Brazil/University clinic	Cross-sectional	132	4.92:1	36.5 (±13.5)	Unclear	Unclear	Impaired mastication: 79.51%; Masticatory fatigue: 33.73%	RDC/TMD, OHIP-14, clinical exam, temporomandibular index	13/16
Radke et al., [36]/2014/ Unclear/Unclear	Descriptive observational	28	1:1	34.5 (±14.0)	Unclear	Unclear	Impaired mastication: 100%	RDC/TMD, magnetic incisor point tracking	7/16
Gonçalves et al., [40]/ 2011/Brazil/University hospital clinic	Case-control	28	28:0	Unclear	Unclear	Unclear	Impaired mastication: 0%	RDC/TMD, anthropomorphic assess-ment, ovulation prediction test, maximum occlusal force, sieve method assessment of masticatory performance	15/18
Brandini et al., [54]/2011/ Australia/Unspecified hospital	Case-control	15	15:0	31.3 (±10.8)	Unclear	Unclear	Impaired mastication: 60%	RDC/TMD, chewing task, numerical rating scale-II, Pain Self-efficacy Questionnaire, Fear-Pain Questionnaire-III, DAS-44, PCS	13/18
Reiszmann et al., [31]/ 2007/Germany/ University clinic	Case-control	312	3.16:1	38.6 (±15.6)	Unclear	Unclear	Impaired mastication: 82.07%; Masticatory pain: 68.53%; Masticatory fatigue: 45.91%	RDC/TMD, German version of OHIP, GCPS, Beschwerden-Liste, the Center for Epidemiologic Studies Depression Scale	10/18
Gavish et al., [38]/2002/ Israel/University clinic	Prospective cohort	49	2.76:1	29.2 (±7.8)	Unclear	Unclear	Masticatory pain: 83.67%;	RDC/TMD, clinical exam, experimental chewing task, palpation, visual analogue scale	16/18
Michelotti et al., [44]/ 2002/Italy/University clinic	RCT	63	Unclear	Unclear	Unclear	Unclear	Masticatory pain: 100%	RDC/TMD, anamnestic and clinical scores, measures of pressure pain thresholds, pain during gum chew-ing, and spontaneous pain, visual analogue scales	4/18

Table 2. Diagnoses of participants eligible for inclusion.

Diagnosis	Osteoarthrosis	Disc displacement with reduction + myofascial pain	Disc displacement/ osteoarthrosis	Myofascial pain + osteoarthrosis++ Arthralgia	Disc displacement without reduction + arthralgia	Disc displacement with reduction + myalgia	Myalgia	Osteoarthrosis	Myofascial pain+ Disc displacement with reduction/ Osteoarthritis	Disc displacement without reduction	Arthralgia	Disc displacement with reduction	Myofascial pain
Number of TMJ diagnoses reported (n = 1623)	13	30	32	34	34	40	58	59	91	95	190	275	672

Table 3. Down's and Black checklist rating criteria.

Descriptor	Criteria for studies with comparison group	Criteria for studies with no comparison group
Poor quality	0–4	0–3
Fair quality	5–9	4–7
Moderate quality	10–14	8–11
Good quality	15–18	12–16

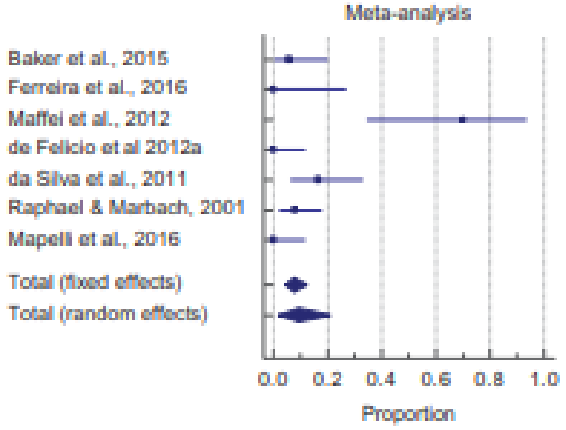

Figure 2. Forest plot of prevalence of impaired swallowing.

Masticatory fatigue was reported in five studies ($n = 577$ patients) [31–33,35,42], with prevalence calculated to be 61.95% (95% CI: 34.16–86.03%) (Figure 5).

No eligible records were identified which estimated the prevalence of weight loss in the cohort of interest, thus preventing analysis.

Discussion

This systematic review and meta-analysis has highlighted that a broad range of signs and symptoms of OD are frequently reported by adult patients with TMDs, although this condition has typically received limited amounts of clinical and research attention. Interestingly, despite this broad range of reported difficulties, the primary outcome under investigation, impaired swallowing, was detected in only 9.3% of included participants. However, potentially contributing to this low prevalence, studies which were eligible for inclusion were assessed to be heterogeneous, which may result in the true prevalence being higher than that estimated within this study. Also, the method by which swallowing was assessed in primary studies may have influenced the overall prevalence estimate, with all eligible studies [32,34,41,49,50,52,53] using subjective assessments, which had varied psychometric properties and were unspecified in certain studies [49,50,53]. The observed reliance on unspecified and varied subjective measures emphasizes the need for both improvements in the reporting of the details and psychometric properties of subjective outcome measurements used, and the frequency of use of objective tools within primary epidemiology studies. Finally, theoretical issues may also impact negatively on the homogeneity, validity, and reliability of research findings in this field. For example: differing theoretical definitions of

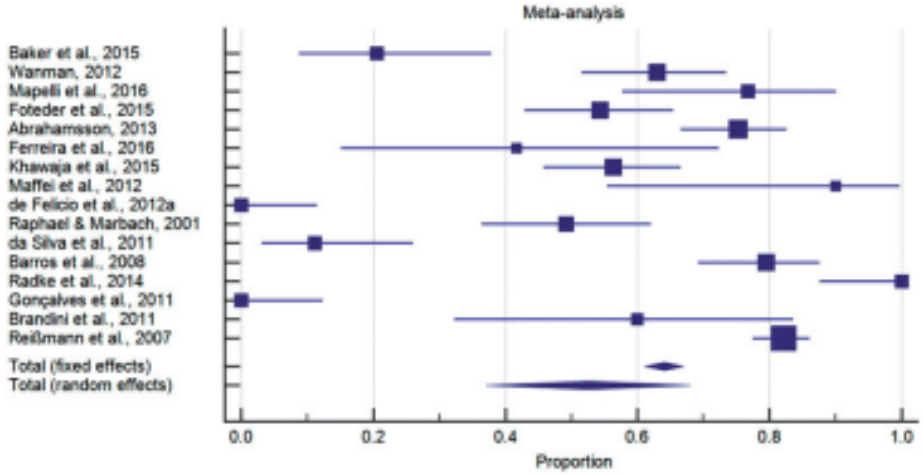

Figure 3. Forest plot of prevalence of impaired mastication.

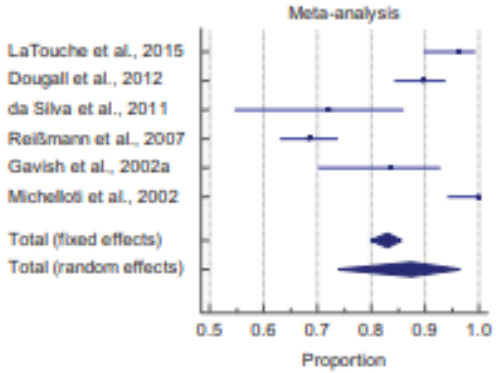

Figure 4. Forest plot of prevalence of masticatory pain.

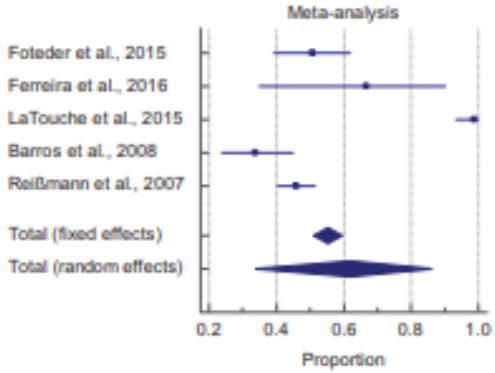

Figure 5. Forest plot of prevalence of masticatory fatigue.

what constitutes a diagnosis of swallowing difficulties in this patient group have been adopted, and many studies which have investigated this parameter have not specified their operational definition of 'impaired deglutition' (e.g. impaired transit of the bolus from the oral to the pharyngeal cavity, impaired triggering of the pharyngeal swallow, or impaired protection of the airway, etc.). As such, in critical analysis of studies conducted in this field, researchers are limited in their ability to construct a cohesive picture of findings due to these limitations. As dysphagia caused by a range of aetiologies has documented effects on functioning, levels of activity and participation, and QOL [55], it is essential that this condition receives greater attention within the field of TMD research.

In addition to the investigation of the primary outcome of deglutition, a range of other signs and symptoms were also investigated. For example: impaired mastication was estimated to be experienced by approximately 53% of adult patients presenting with TMDs in this study. However, only 50% of the eligible studies which reported figures on impaired mastication [32,34,37,40,43,50,52] collected data using chewing performance or endurance tasks, with the remaining studies relying on subjective patient reports [31,33,35,36,41,49,51,53]. As such, there is the potential for the under-identification of perceptually mild masticatory impairments when only subjective data are collected.

However, masticatory impairments are often considered central to the experience of TMDs and therefore, these findings may not be viewed as novel. Yet, it is crucial to note that specific aspects of chewing difficulties have infrequently been discussed in the literature (e.g. masticatory pain or fatigue). In this study, masticatory pain was estimated to be experienced by 87% of individuals, indicating that this may be a commonly experienced difficulty, although the precise pathophysiology of this pain and discomfort across TMD diagnostic classifications is unknown. In addition, masticatory fatigue was present in approximately 62% of individuals with TMDs, as measured using primarily subjective measures [31–33,35,42]. Individuals with chronic pain and related-central sensitization conditions frequently report fatigue as being a primary determinant of well-being, with chronic fatigue being cited as a mediating factor in the relationship between functioning, pain and QOL [56]. However, despite the perceived significance of this symptom, masticatory fatigue

attributed to TMD-related OD has been minimally investigated, and no eligible studies reported prevalence rates using EMG to objectively measure indices of muscle fatigue, endurance and exercise tolerance. As such, although this study provides new evidence regarding the spectrum of possible chewing difficulties beyond that which had been previously discussed, it is evident that further research in this field is required.

Limitations

One limitation of this study was that few records satisfied this systematic review's inclusion criteria. For example: while primary studies reported that patients presented with TMDs, few provided sufficient demographic or diagnostic information (e.g. gender, mean age, DDWR, MFP, etc.) to allow for statistical stratification, with information unavailable on author contact attempts, also. This resulted in the forced exclusion of a large number of studies which may have positively influenced ultimate study findings. Therefore, results are derived from a limited, and potentially unrepresentative, cohort of heterogeneous primary records, with potential for confounding. As such, it is recommended that large-scale psychometrically valid and reliable epidemiological research is conducted in this field to adequate address concerns. A further limitation of this review is the lack of studies which utilised objective measures as sources of assessment data. The heavy reliance on subjective measures alone observed within primary studies in this review may be concerning due to the variable psychometric properties of these tools and their increased potential for the introduction of observer, recall, and detection bias. As such, it is recommended that future studies employ a combination of both subjective patient-report and objective imaging techniques.

Recommendations

Due to the identified high prevalence and varied nature of a range of OD signs and symptoms in adults with TMDs, it is recommended that future robust epidemiological research is conducted in order to both further our understanding of this condition, and to provide a valid and reliable foundation on which subsequent avenues for clinical improvements may be built. In order to appropriately investigate TMD-related OD within future research and clinical contexts, it is also advised that a cohort-specific simple and efficient assessment tool with adequate psychometric properties is developed for use with this patient group. Finally, in order to ensure that the spectrum of potential signs and symptoms of TMD-related OD are identified during definitive evaluations, it is suggested that a broad based assessment protocol is also developed, which encompasses subjective patient reports, functional chewing tasks, and objective assessment measures, as appropriate.

Conclusions

This systematic review and meta-analysis has highlighted that signs and symptoms of OD are consistently reported by adults presenting with a range of TMD diagnoses. It has also identified a spectrum of methodological limitations within the available literature. This review has, therefore, indicated the need for psychometrically robust epidemiological research which investigates the presence, nature, and impact of TMD-related OD in a valid and reliable manner.

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Disclosure statement

The authors have no conflicts of interest to declare.

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Appendix 1. Example of database search strategy for PubMed

('Deglutition'[Mesh] OR 'Deglutition Disorders'[Mesh] OR Dysphagia[Title/Abstract] OR Dysphagic[Title/Abstract] OR Deglutition[Title/Abstract] OR Swallow[Title/Abstract] OR Swallows[Title/Abstract] OR Swallowing[Title/Abstract] OR Swallowed[Title/Abstract]) AND ('Mandible'[Mesh] OR 'Temporomandibular Joint'[Mesh] OR 'Temporomandibular Joint Disorders'[Mesh] OR 'Stomatognathic System Abnormalities'[Mesh] OR 'Skull'[Mesh] OR 'Jaw'[Mesh] OR 'Mastication'[Mesh] OR 'Mouth Opening'[Title/Abstract] OR Mandibular[Title/Abstract] OR Mandible[Title/Abstract] OR Temporomandibular[Title/Abstract] OR Stomatognathic[Title/Abstract] OR Masticatory[Title/Abstract] OR Mastication[Title/Abstract] OR Jaw[Title/Abstract] OR Jaws[Title/Abstract] OR Skull[Title/Abstract] OR Skulls[Title/Abstract] OR Cranium[Title/Abstract] OR Calvaria[Title/Abstract] OR Calvarium[Title/Abstract]).

Appendix 2. Down's and Black checklist

	Yes (1 point)	No (0 points)	Unclear (0 points)
Hypothesis/aim/objective explicit			
Main outcomes clearly described in the introduction or methods section			
Characteristics of patients included clearly described			
Distributions of principal confounders in each group of subjects to be compared clearly described[a]			
Main findings clearly described			
Study provides estimates of random variability for main outcomes			
Characteristics of patients lost to follow-up described			
Actual probability values been reported for main outcomes except where probability value is less than 0.001			
Subjects representative of entire population			
Subjects prepared to participate representative of entire population			
Staff, places, and facilities representative			
Any of the results of the study were based on 'data dredging'			
Appropriate statistical tests used to assess main outcomes			
Main outcome measures used accurate (valid and reliable)			
Adequate adjustment for confounding in the analyses			
Patients in different groups or cases and controls recruited from same population			
Subjects in different groups or cases and controls recruited over same time			

[a]Yes: 2 points; Partially: 1 point; No: 0 points.

Appendix 5: Search Strategy: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

("Deglutition"[Mesh] OR "Deglutition Disorders"[Mesh] OR Dysphagia[Title/Abstract] OR Dysphagic[Title/Abstract] OR Deglutition[Title/Abstract] OR Swallow[Title/Abstract] OR Swallows[Title/Abstract] OR Swallowing[Title/Abstract] OR Swallowed[Title/Abstract]) AND ("Mandible"[Mesh] OR "Temporomandibular Joint"[Mesh] OR "Temporomandibular Joint Disorders"[Mesh] OR "Stomatognathic System Abnormalities"[Mesh] OR "Skull"[Mesh] OR "Jaw"[Mesh] OR "Mastication"[Mesh] OR "Mouth Opening"[Title/Abstract] OR Mandibular[Title/Abstract] OR Mandible[Title/Abstract] OR Temporomandibular[Title/Abstract] OR Stomatognathic[Title/Abstract] OR Masticatory[Title/Abstract] OR Mastication[Title/Abstract] OR Jaw[Title/Abstract] OR Jaws[Title/Abstract] OR Skull[Title/Abstract] OR Skulls[Title/Abstract] OR Cranium[Title/Abstract] OR Calvaria[Title/Abstract] OR Calvarium[Title/Abstract]).

Appendix 6: Data Extraction Form: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

- Reviewer –
- Study ID/Record Number -
- Date –

Study details

- Citation -
- Language -
- Aims of the study –

Study Method

- Setting –
- Study design –
- Participant demographics –
- Recruitment procedure –
- Target population and final number of subjects studied for –
- Follow-up or study duration –
- Inclusion/Exclusion criteria –
- Dependent variable –
- Description of measurement of exposure and outcome (e.g. instrument, protocol, reliability) –
- Outcomes –
- Outcome measurements –
- Length of follow-up –
- Ethical approval –
- Method of data analysis –

Results

- Statistical techniques used (e.g. regression, t-tests) –
- Confounding factors adjusted for -
- Prevalence n/N (%) –
- Incidence n/N (%) –
- Study conclusion –

Authors' comments

Reviewer comments

Appendix 7: Downs and Black Assessment of Methodological Quality: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

	Yes (1 point)	No (0 points)	Unclear (0 points)
Hypothesis/aim/objective explicit			
Main outcomes clearly described in the Introduction or Methods section			
Characteristics of patients included clearly described			
Distributions of principal confounders in each group of subjects to be compared clearly described*			
Main findings clearly described			
Study provides estimates of random variability for main outcomes			
Characteristics of patients lost to follow-up described			
Actual probability values been reported for main outcomes except where probability value is less than 0.001			
Subjects representative of entire population			
Subjects prepared to participate representative of entire population			
Staff, places, and facilities representative			
Any of the results of the study were based on "data dredging"			
Appropriate statistical tests used to assess main outcomes			
Main outcomes measured using accurate tools			
Adequate adjustment for confounding in the analyses			
Patients in different groups or cases and controls recruited from same population			
Subjects in different groups or cases and controls recruited over same time			

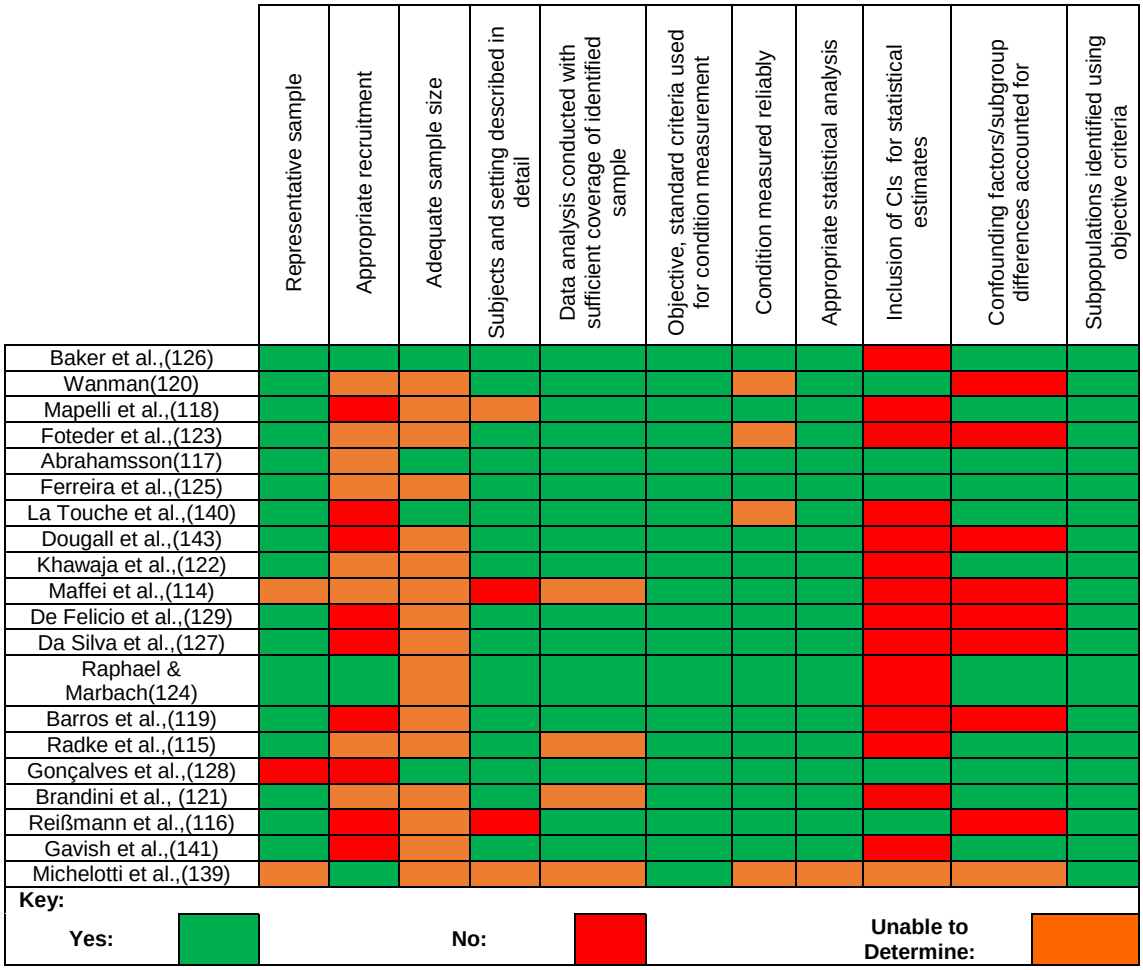
**Yes=2 points; partially=1 point; no=0 points*

Appendix 8: Boyle-JBI Tool: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

	Yes (1 point)	No (0 points)	Unclear (0 points)
Representative sample			
Appropriate recruitment			
Adequate sample size			
Subjects and setting described in detail			
Data analysis conducted with sufficient coverage of identified sample			
Objective, standard criteria used for condition measurement			
Condition measured reliably			
Appropriate statistical analysis			
Inclusion of confidence intervals for statistical estimates			
Confounding factors/subgroup differences accounted for			
Subpopulations identified using objective criteria			

Appendix 9: Boyle-JBI Data: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders: A Systematic Review and Meta-analysis

Boyle-JBI Methodological Quality Risk of Bias Table



Boyle-JBI Tool Scoring of Included Studies

Study Name	Score Awarded	Rating Awarded
Baker et al.,(126)	10	Good quality
Wanman(120)	7	Moderate quality
Mapelli et al.,(118)	7	Moderate quality
Foteder et al.,(123)	6	Moderate quality
Abrahamsson(117)	10	Good quality
Ferreira et al.,(125)	9	Good quality
La Touche et al.,(140)	8	Moderate quality
Dougall et al.,(143)	7	Moderate quality
Khawaja et al.,(122)	8	Moderate quality
Maffei et al.,(114)	4	Fair quality
De Felicio et al.,(129)	7	Moderate quality
Da Silva et al.,(127)	7	Moderate quality
Raphael & Marbach(124)	9	Good quality
Barros et al.,(119)	7	Moderate quality
Radke et al.,(115)	7	Moderate quality
Gonçalves et al.,(128)	9	Good quality
Brandini et al., (121)	7	Moderate quality
Reißmann et al.,(116)	7	Moderate quality
Gavish et al.,(141)	8	Moderate quality
Michelotti et al.,(139)	3	Fair quality

Boyle-JBI Tool Rating Criteria

Descriptor	Criteria
Poor Quality	0-2
Fair Quality	3-5
Moderate Quality	6-8
Good Quality	9-11

Appendix 10: Associated Publication: The Prevalence, Nature, and Management of Eating and Swallowing problems in Adults with Temporomandibular Disorders: Findings from an Irish Cohort

ANESTHESIA/FACIAL PAIN

Prevalence, Nature, and Management of Oral Stage Dysphagia in Adults With Temporomandibular Joint Disorders: Findings From an Irish Cohort

Órla Gilbeaney, MSc, BSc, * *Leo FA Stassen, MB, BCH, BAO, BDentSc,* † *and Margaret Walsbe, PhD, MSc, BA* ‡

Purpose: Temporomandibular disorders (TMDs) are caused by changes in the structure and/or function of the temporomandibular joint, masticatory muscles, and/or osseous components. TMDs can result in oral stage dysphagia (OD) with potential effects on function and patient well-being. Little is known about the prevalence, nature, and management of TMD-related OD. The aims of the present study were to estimate the prevalence and nature of OD in adult TMD patients and to identify the common management techniques used to manage the signs and symptoms of TMD-related OD.

Patients and Methods: An 18-item subjective questionnaire was adapted from existing tools and used to investigate TMD etiology, the symptoms and signs of TMD-related OD, and the intervention techniques used to manage these symptoms. This was disseminated to 178 TMD patients consecutively recruited over 6 months in 2016. Descriptive and statistical methods were used to analyze the data.

Results: Of the 178 TMD participants, 99% reported at least one symptom or sign of OD. Individuals presenting with subluxation of the jaw (80%), degenerative joint disorder (67%), and myofascial pain disorder (40%) reported OD most frequently. Common symptoms included painful mastication (90%), masticatory fatigue (78%), difficulties swallowing (33%), and difficulties drinking liquids (28%). The use of a broad range of management techniques was reported, with these including both OD-specific techniques (eg, diet modifications [81%]), and non-OD specific techniques (eg, analgesia [79%] and oral splints [75%]).

Conclusions: OD is prevalent, and difficulties with mastication are common in those with TMDs. The interventions used were diverse, with varying objectives and disparate levels of evidence supporting their efficacy within this cohort. Further research should address the epidemiology of TMD-related OD, evidence-based interventions, and the promotion of collaboration across the disciplines responsible for managing TMD-related OD (eg, speech and language therapy, oral and maxillofacial surgery, dentistry, restorative dentistry, orthodontics, oral medicine).

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Temporomandibular disorders (TMDs) are a range of heterogeneous conditions characterized by pain and dysfunction of the temporomandibular joint (TMJ) complex, due to alterations in the structure and/or function of the TMJ, wider masticatory muscle system, and/or osseous components.[1-4] TMDs are the second most common musculoskeletal and neuromuscular disorder after lower back pain, with up to 93% of the

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Conflict of Interest Disclosures: None of the authors have any relevant financial relationship(s) with a commercial interest.

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general population reporting at least one sign or symptom (eg, joint pain, pain on palpation, movement-induced fatigue).[5-8] TMDs, therefore, place large burdens on global economic and healthcare systems, costing the American exchequer an approximate $4 billion per annum,[2] although no economic data exist to quantify the specific cost to the Irish exchequer. However, despite the reported frequency of TMD symptoms and signs in both clinical and typical cohorts, precise prevalence estimates of oral stage dysphagia (OD) have not been established owing to the use of varying classification systems, assessment tools, and definitions.[9]

Symptoms and signs of TMDs such as limited mandibular movement and pain/fatigue on functioning can result in OD.[10,11] OD has been reported across the etiologic spectrum of TMDs, with recent systematic review estimations of impaired swallowing in up to 25% of adult patients with TMDs, masticatory pain in up to 79%, fatigue in up to 56%, and impaired mastication in up to 53% of patients.[10,11] However, limited amounts of heterogeneous evidence were available for inclusion in these pooled analyses, and amalgamation of the evidence was also hampered by variations in the terminology used, symptoms considered clinically relevant, research method used, diagnostic systems applied, and methods of data collection.[12] As such, the true prevalence rates might be greater than the estimations presented. Consequentially, it has been advocated that TMD-related OD should be investigated across the range of TMD diagnostic subtypes, in representative clinical populations, to generate in-depth epidemiologic estimates. Such estimates might subsequently highlight the need for the development of service delivery structures, inclusive care pathways, and evidence-based interventions.[13]

In conjunction with difficulties in the amalgamation and interpretation of the available reported research, it has been suggested that difficulties also exist in relation to the management of TMD-related OD (Gilheaney O, Stassen LFA, Walshe M: Oral stage dysphagia and temporomandibular disorders: Irish dental professionals'perspectives on management. Manuscript in Preparation; Gilheaney O, Walshe M: Rheumatologist's perspectives regarding oral stage dysphagia associated with rheumatoid arthritis-related temporomandibular disorders. Manuscript in Preparation). These issues could relate to low levels of perceived significance and awareness of this condition by frontline clinicians, the lack of cohort-specific assessment and management tools for use with these patients, and low levels of reported clinician satisfaction with the current standards of care provided (Gilheaney O, Stassen LFA, Walshe M: Oral stage dysphagia and temporomandibular disorders: Irish dental professionals'perspectives on management. Manuscript in Preparation; Gilheaney O, Walshe M: Rheumatologist's perspectives regarding oral stage dysphagia associated with rheumatoid arthritis-related temporomandibular disorders. Manuscript in Preparation). No research to date has addressed the development of evidence-based intervention techniques for the management of TMD-related OD. Therefore, clinicians must rely on a varied range of nonspecific intervention strategies spanning a myriad of disciplines (eg, medicine, dentistry, surgery) which have limited supporting evidence for their efficacy or effectiveness. As such, further research into the current and optimal management of TMD-related OD in adult patients is warranted.

Therefore, the aims of the present study were to determine the prevalence and nature of TMD-related OD symptoms and signs in adult treatment-seeking TMD patients and to examine the common management techniques used by these patients to improve difficulties in eating, drinking, and swallowing.

Patients and Methods

The St. James's Hospital joint research ethics committee granted ethical approval for the present study. A prospective cross-sectional study design was used to investigate the prevalence, nature, and management of TMD-related OD in treatment-seeking adult patients presenting to the Dublin Dental University Hospital and National Maxillofacial Unit in St. James's Hospital (Dublin, Ireland), for TMD management during the 6-month study period (July 2016 to December 2016).

Patients were eligible for inclusion if they had presented to the study locations as consecutive adults, aged 18 years or older, of any gender, race, or TMD severity level, with a diagnosis of TMD in accordance with the reference standard Diagnostic Criteria for Temporomandibular Disorders (DC/TMD)[14] or the previously used Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD)[15] classification system. These classification systems were developed in accordance with the biopsychosocial model of pain, and provide users with a dual-axis diagnostic protocol, which allows clinicians to gather structured, valid, and reliable clinical histories, observations, and assessments of psychosocial functioning across the TMD spectrum.[14-17] Patients were excluded if they were younger than 18 years old or if they presented with a history of relevant comorbid conditions affecting the typical functioning within the mandibular region (eg, orthopedic trauma affecting the mandibular region; cancer of the oral or head and neck region; neurologic disease affecting functioning in this area). Patients were also excluded if they presented with a history of congenital/syndromic characteristics affecting mandibular function.

A new cohort-specific subjective patient questionnaire was developed to investigate the domains of

interest (Appendix 1). The Temporomandibular Disorder Eating, Drinking, and Swallowing Scale (TEDSS) was used to investigate the presence/absence of eating, drinking, and swallowing disorders and their management in adults presenting with TMDs. To survey the specific etiologies of the presenting TMDs, the TEDSS included a diagnostic subscale with the most common joint- and pain-related TMD diagnoses abstracted from the DC/TMD.[14] The DC/TMD diagnostic classification system reliably differentiates between the most frequent pain-related TMDs (sensitivity ≥0.86, specificity ≥0.98).[14] In addition, a symptoms and signs subscale was adapted from the Jaw Functional Limitation Scale (JFLS)[18] and the DC/TMD assessment tool.[14] The JFLS is a self-report measure that assesses difficulties related to mastication and jaw mobility, among other facets.[18,19] Ten items relating to chewing, swallowing, drinking, weight loss, and diet modification were extracted from the mastication subscale of the JFLS, which has established psychometric properties as a standalone scale (item reliability 0.95; person reliability 0.86; Cronbach's α 0.83).[18] Finally, a management subscale was developed that sought information regarding the intervention strategies the participant had used to manage symptoms of TMD-related OD. This subscale was developed through a comprehensive literature review regarding commonly used TMD, OD, and chronic pain management techniques. Completion of the assessment protocol required approximately 5 minutes total.

Descriptive statistics were used to summarize all demographic data. Age, gender, and diagnosis-specific prevalence and the overall rates of OD were also descriptively calculated. Statistical analysis was completed using nonparametric Mann-Whitney *U* and post hoc Kruskal-Wallis tests, with Bonferroni's correction conducted and calculation of Spearman's rank correlation coefficient.

Results

We disseminated 182 surveys to patients presenting to the clinical sites during the study period, with 178 ultimately participating, yielding a 98% response rate.

RESPONDENT DEMOGRAPHIC DATA

The respondent characteristics are listed in Table 1. The overall age range was 18 to 92 years (mean 43 ± 17). Of the 178 participants, 142 were women (805) and 36 were men (20%), for a female/male ratio of 4:1. Joint-related disorders were experienced by one half of all participants (n = 91 [51%]), predominantly by women (74 women and 17 men). Disc displacements were the most frequently reported joint-related diagnoses, with disc displacements with reduction and without reduction experienced by 47 (26%) and 30 (17%) patients, respectively. Pain-related disorders were reported by 66 participants (37%), with high levels of female representation (57 women; 9 men). Myofascial pain disorder (MFP) was the most frequent pain-related diagnosis (20% of the overall sample [n = 35]). The etiology of TMDs was unknown for 21 patients (12%).

SYMPTOMS OF EATING, DRINKING, AND SWALLOWING DISORDERS

Most participants (n = 176 [99%]) reported at least 1 symptom or sign of OD. Difficulty swallowing was reported by 59 of all participants (33%; Table 2). Dysphagia for liquids was reported by 49 respondents

Table 1. DEMOGRAPHIC DATA OF SURVEY POPULATION (N = 178)

	Age (yr)			Sex (n)	
Characteristic	Mean ± SD	Median	Range	Male	Female
Overall sample	43.196 ± 16.79	43	18-92	36	142
Arthralgia	56.25 ± 13.41	55.5	40-81	2	6
Myalgia	43.55 ± 15.66	44	18-70	3	17
Myofascial pain disorder	50.73 ± 17.64	49	23-92	3	32
Headache attributed to TMD	40 ± 7.93	43	31-46	1	2
DDWR	35.71 ± 12.73	36	18-61	9	38
DDWOR	38.03 ± 14.06	36	18-65	5	25
Degenerative joint disease	54.66 ± 21.36	67	30-67	1	2
Rheumatoid arthritis	61 ± 11.34	62	43-72	1	5
Subluxation	39.6 ± 28.69	32	18-88	1	4
Unknown	41 ± 14.95	39	18-65	10	11

Abbreviations: DDWOR, disc displacement without reduction; DDWR, disc displacement with reduction; SD, standard deviation; TMD, temporomandibular disorder.

Table 2. INVESTIGATED SYMPTOMS OF EATING, DRINKING, AND SWALLOWING DISORDERS

Symptom	Overall Sample (n)	Arthralgia	Myalgia	MFP	Headache Attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Difficulty swallowing	33.14 (59)	37.5 (3)	20 (4)	40 (14)	0 (0)	34.09 (15)	23.4 (11)	66.6 (2)	0 (0)	80 (4)	28.5 (6)
Difficulty drinking	27.52 (49)	37.5 (3)	20 (4)	40 (14)	0 (0)	27.65 (13)	23.33 (7)	66.6 (2)	0 (0)	80 (4)	9.52 (2)
Difficulty chewing hard/ crunchy food	89.32 (159)	75 (6)	90 (18)	94.28 (33)	66.6 (2)	95.74 (45)	90 (27)	100 (3)	83.33 (5)	100 (5)	71.42 (15)
Difficulty chewing soft food	58.42 (104)	62.5 (5)	45 (9)	74.28 (26)	0 (0)	55.31 (26)	60 (18)	100 (3)	50 (3)	80 (4)	42.85 (9)
Difficulty eating food that requires little/no chewing	23.59 (42)	25 (2)	15 (3)	31.42 (11)	0 (0)	25.53 (12)	23.3 (7)	0 (0)	33.3 (2)	40 (2)	14.28 (3)
Pain on chewing	89.88 (160)	75 (6)	85 (17)	97.14 (34)	66.6 (2)	97.87 (46)	86.66 (26)	100 (3)	50 (3)	80 (4)	90.47 (19)
Tiredness on chewing	78.08 (139)	75 (6)	60 (12)	90 (27)	100 (3)	78.72 (37)	86.66 (26)	100 (3)	66.6 (4)	100 (5)	76.19 (16)
Weight loss due to difficulties with eating and drinking	26.4 (47)	12.5 (1)	20 (4)	34.28 (12)	0 (0)	17.02 (8)	40 (12)	66.6 (2)	16.66 (1)	0 (0)	33.3 (7)

Data presented as % (n).

Abbreviations: DDWOR, disc displacement without reduction; DDWR, disc displacement with reduction; DJD, degenerative joint disease; MFP, myofascial pain disorder; RA, rheumatoid arthritis; TMD, temporomandibular disorder.

Gilbreath, Stassen, and Wahlbe. OD in Adults With TMDs. J Oral Maxillofac Surg 2018.

(28%), which might have been related to difficulties opening the mouth wide enough to drink from a standard cup or glass. Depending on the food consistency, difficulties chewing hard or crunchy food were reported by 159 (89%), and difficulties chewing soft food were reported by 104 (58%). Difficulties chewing food that required minimal chewing was reported by 42 (24%). Impaired mastication across food consistencies was reported to a greater degree by participants with joint-related disorders. Pain on mastication was reported by 160 patients (90%), and masticatory fatigue was experienced by 139 (78%). Weight loss attributed to OD was experienced by 47 respondents (26%).

Participants also reported a spectrum of OD symptoms using the "other" section of the TEDSS questionnaire. These were stratified into 5 broad categories and included masticatory, oromotor, pain, audiologic, and psychosocial symptoms (Table 3). One half of the participants reported unilateral (n = 98 [55%]) and slow (n = 88 [49%]) mastication, and one fifth (n = 31 [17%]) reported being able to masticate only soft, preprocessed foods and, subsequently, unintentionally gaining weight. The psychosocial consequences of OD were also highlighted, with 78 (44%) experiencing anxiety and/or embarrassment regarding their OD, with data trends suggesting that this a symptom experienced most by those with pain-related disorders. Almost one half of the participants (n = 74 [42%]) reported avoiding all social interaction at the peak of TMD-related OD symptom severity.

Statistical analysis using Mann-Whitney *U* tests indicated statistically significant differences in the number of TMD-related OD symptoms reported by participants presenting with either joint- or pain-related TMDs ($U = 2767$; $P = .53$). Results from a Kruskal-Wallis H test revealed statistically significant differences in the number of symptoms reported by participants presenting with different TMD diagnoses [eg, disc displacements, MFP, or myalgia; $\chi^2(8) = 24.49$; $P = .002$]. However, post hoc pairwise Mann-Whitney *U* tests with Bonferroni's correction demonstrated no statistically significant differences between the diagnostic pairings, potentially due to the increased post hoc conservative adjustment for errors and the large number of secondary pairwise comparisons completed. Finally, no statistically significant gender differences between the number of TMD-related OD signs and symptoms reported by the male and female patients were detected ($U = 2470$; $P = .752$).

MANAGEMENT OF SYMPTOMS OF EATING, DRINKING, AND SWALLOWING DISORDERS

Most participants reported the use of poly-modal interventions (n = 165 [93%]), with a few reporting the sole use of 1 unimodal intervention technique (n = 8

Table 3. OTHER SYMPTOMS OF EATING, DRINKING, AND SWALLOWING DISORDERS

Other Symptoms	Overall Sample	Arthralgia	Myalgia	MFP	Headache Attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Masticatory symptoms											
Slowed mastication	49.43 (88)	62.5 (5)	35 (7)	68.57 (24)	0 (0)	63.82 (30)	46.66 (14)	66.6 (2)	16.6 (1)	80 (4)	4.76 (1)
Unilateral mastication	55.05 (98)	75 (6)	45 (9)	71.4 (25)	0 (0)	76.59 (36)	53.3 (16)	66.6 (2)	16.6 (1)	60 (3)	0 (0)
Restricted to eating soft nutritionally unbalanced foods and gaining weight	17.41 (31)	0 (0)	15 (3)	34.28 (12)	0 (0)	19.14 (9)	16.66 (5)	0 (0)	0 (0)	20 (1)	4.76 (1)
Oromotor symptoms											
Drooling	3.37 (6)	0 (0)	5 (1)	5.71 (2)	0 (0)	2.12 (1)	0 (0)	0 (0)	0 (0)	20 (1)	4.76 (1)
Slurred speech	33.7 (60)	62.5 (5)	15 (3)	40 (14)	0 (0)	42.55 (20)	33.3 (10)	33.3 (1)	16.6 (1)	40 (2)	19.04 (4)
Painful speech	43.82 (78)	62.5 (5)	30 (6)	51.42 (18)	0 (0)	55.31 (26)	46.6 (14)	33.3 (1)	16.6 (1)	60 (3)	19.04 (4)
Difficulties laughing	43.25 (77)	37.5 (3)	20 (4)	57.14 (20)	0 (0)	61.7 (29)	53.3 (16)	33.3 (1)	16.6 (1)	60 (3)	0 (0)
Difficulties singing	39.32 (70)	50 (4)	15 (3)	54.28 (19)	0 (0)	55.31 (26)	40 (12)	33.3 (1)	16.6 (1)	60 (3)	4.76 (1)
Difficulties kissing	11.79 (21)	0 (0)	10 (2)	11.42 (4)	0 (0)	14.89 (7)	23.3 (7)	0 (0)	0 (0)	20 (1)	0 (0)
Bruxism	56.17 (100)	50 (4)	35 (7)	71.42 (25)	0 (0)	74.46 (35)	63.33 (19)	66.6 (2)	16.6 (1)	100 (5)	4.76 (1)
Occlusal changes	8.98 (16)	25 (2)	15 (3)	8.57 (3)	0 (0)	4.25 (2)	13.3 (4)	0 (0)	0 (0)	0 (0)	9.52 (2)
Pain symptoms											
Migraines or headaches	39.88 (71)	37.5 (3)	35 (7)	48.57 (17)	100 (3)	48.93 (23)	46.6 (14)	33.3 (1)	0 (0)	20 (1)	9.52 (2)
Auricular pain	32 (57)	25 (2)	25 (5)	42.9 (15)	0 (0)	46.8 (22)	33.3 (10)	33.3 (1)	0 (0)	20 (1)	4.76 (1)
Audiologic symptoms											
Hearing loss	5.1 (9)	0 (0)	0 (0)	2.9 (1)	0 (0)	6.4 (3)	10 (2)	33.3 (1)	0 (0)	0 (0)	9.52 (2)
Tinnitus	5.1 (9)	0 (0)	5 (1)	2.9 (1)	0 (0)	6.4 (3)	10 (2)	33.3 (1)	0 (0)	0 (0)	4.76 (1)
Psychosocial symptoms											
Difficulties concentrating	23 (41)	12.5 (1)	10 (2)	40 (14)	0 (0)	29.8 (14)	20 (6)	66.6 (2)	0 (0)	20 (1)	4.76 (1)
Anxious or embarrassed about people noticing difficulties	43.82 (78)	62.5 (5)	25 (5)	51.42 (18)	0 (0)	44.7 (21)	56.7 (17)	33.3 (1)	0 (0)	20 (1)	23.8 (5)
Avoidance of social situations	41.57 (74)	62.5 (5)	25 (5)	48.57 (17)	0 (0)	46.8 (22)	56.7 (17)	66.6 (2)	0 (0)	20 (1)	23.8 (5)
Avoidance of occupational situations	26.4 (47)	37.5 (3)	15 (3)	42.9 (15)	0 (0)	29.8 (14)	33.3 (10)	33.3 (1)	0 (0)	20 (1)	0 (0)
Relationship difficulties	30.9 (55)	37.5 (3)	10 (2)	48.6 (17)	0 (0)	31.9 (15)	50 (15)	33.3 (1)	0 (0)	20 (1)	4.76 (1)
Sleep disturbances	57.8 (102)	75 (6)	45 (9)	62.9 (22)	0 (0)	70.2 (33)	70 (21)	33.3 (1)	16.6 (1)	100 (5)	19 (4)
Difficulties exercising	6.7 (12)	0 (0)	10 (2)	5.7 (2)	0 (0)	8.5 (4)	6.7 (2)	0 (0)	16.6 (1)	20 (1)	0 (0)
Suicidal ideation	3.4 (6)	12.5 (1)	0 (0)	2.9 (1)	0 (0)	4.25 (2)	3.3 (1)	0 (0)	0 (0)	0 (0)	4.76 (1)

Data presented as % (n).

Abbreviations: DDWOR, disc displacement without reduction; DDWR, disc displacement with reduction; DJD, degenerative joint disease; MFP, myofascial pain disorder; RA, rheumatoid arthritis; TMD, temporomandibular disorder.

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[4%]), or no intervention at all (n = 5 [3%]). Diet modifications were the most frequently used management technique in 145 participants (81%), followed by pain relief medication (n = 140 [79%]), and oral splints (n = 133 [75%]; Table 4). More than one half (n = 110 [62%]) had been advised to perform rehabilitative exercises by the clinicians practicing in the recruitment locations. One third (n = 59 [33%]) used adapted feeding utensils, with the use of straws reported most often (n = 43 [24%]). Overall, of the interventions specifically listed in the TEDSS Management subscale, acupuncture was the least frequently used intervention (n = 27 [15%]), with those experiencing pain-related disorders using this intervention more frequently than those with joint-related disorders.

Participants also reported using a range of "other" intervention strategies (Table 5). The most frequently used technique was complete avoidance of eating when symptoms were at their worst (n = 152 [85%]), with trends indicating that participants with joint-related diagnoses avoided eating to the greatest degree. The use of conservative measures, including heat packs (n = 89 [50%]), self-massage (n = 63 [35%]), avoiding talking (n = 45 [25%]), and ice packs (n = 42 [24%]), were also reported. Surgery was used in cases of nonrefractory TMDs, with arthrocentesis and eminectomy the most commonly used methods (n = 29 [16%] and n = 14 [8%], respectively). Finally, relaxation techniques (eg, nonspecific meditation, relaxing music, and guided imagery techniques) were used by one fifth of the respondents (n = 32 [18%]).

The results of a Mann-Whitney *U* test indicated that no significant gender differences were present in the overall number of management techniques used by the female or male participants ($U = 2178$; $P = .164$) or in the number of techniques used by the participants presenting with pain or joint disorders ($U = 2474.5$; $P = .08$). The results of a Kruskal-Wallis H test indicated statistically significant differences in the overall number of management techniques used between participants presenting with different TMD diagnoses [$\chi^2(8) = 17.8$; $P = .023$]. However, post hoc pairwise Mann-Whitney *U* tests with Bonferroni's correction indicated that the absence of statistically significant differences between specific diagnoses. Spearman's rank correlation coefficient was calculated, showing a statistically significant correlation between the overall number of OD symptoms reported and the overall number of management techniques used ($r = 0.51$; $P < .05$).

Discussion

The present study found that within the recruited sample, 99% of adults presenting with TMDs reported at least one sign or symptom of impaired eating,

Table 4. INVESTIGATED MANAGEMENT TECHNIQUES

Management Techniques	Overall Sample	Arthralgia	Myalgia	MFP	Headache Attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Pain management	78.65 (140)	87.5 (7)	85 (17)	80 (28)	66.6 (2)	76.59 (36)	57.5 (23)	100 (3)	83.3 (5)	80 (4)	71.42 (15)
Adapted feeding utensils											
Straws	24.15 (43)	12.5 (1)	35 (7)	28.57 (10)	33.3 (1)	21.27 (10)	23.3 (7)	66.6 (2)	16.66 (1)	60 (3)	4.76 (1)
Bottles	12.92 (23)	12.5 (1)	5 (1)	20 (7)	33.3 (1)	12.76 (6)	6.66 (2)	66.6 (2)	16.66 (1)	40 (2)	0 (0)
Cups	7.86 (14)	12.5 (1)	0 (0)	17.14 (6)	33.3 (1)	6.38 (3)	3.33 (1)	0 (0)	16.66 (1)	20 (1)	0 (0)
Cutlery	21.91 (39)	12.5 (1)	20 (4)	22.85 (8)	33.3 (1)	25.53 (12)	23.33 (7)	66.6 (2)	16.66 (1)	20 (1)	9.52 (2)
Oral splints	74.71 (133)	87.5 (7)	65 (13)	68.57 (24)	100 (3)	91.48 (43)	73.3 (22)	100 (3)	50 (3)	40 (2)	61.9 (13)
Acupuncture	15.16 (27)	12.5 (1)	20 (4)	20 (7)	0 (0)	10.63 (5)	33.3 (10)	0 (0)	0 (0)	0 (0)	0 (0)
Exercises	61.79 (110)	75 (6)	50 (10)	57.14 (20)	66.6 (2)	72.34 (34)	73.33 (22)	100 (3)	33.3 (2)	60 (3)	38.09 (8)
Diet modifications	81.46 (145)	62.5 (5)	85 (17)	85.71 (30)	33.3 (1)	82.97 (39)	80 (24)	100 (3)	66.6 (4)	100 (5)	80.95 (17)

Data presented as % (n).

Abbreviations: DDWOR, disc displacement without reduction; DDWR, disc displacement with reduction; DJD, degenerative joint disease; MFP, myofascial pain disorder; RA, rheumatoid arthritis; TMD, temporomandibular disorder.

Table 5. OTHER MANAGEMENT TECHNIQUES

Other Management Techniques	Overall Sample	Arthralgia	Myalgia	MFP	Headache Attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Thermal interventions											
Ice packs	23.59 (42)	25 (2)	5 (1)	22.85 (8)	0 (0)	34.04 (16)	30 (9)	66.6 (2)	0 (0)	20 (1)	14.28 (3)
Cooling gel	14.04 (25)	0 (0)	5 (1)	17.14 (6)	0 (0)	21.27 (10)	20 (6)	0 (0)	0 (0)	20 (1)	4.76 (1)
Heat packs	50 (89)	50 (4)	25 (5)	42.85 (15)	0 (0)	63.82 (30)	73.3 (22)	66.6 (2)	16.6 (1)	80 (4)	28.57 (6)
Heating gels	23.03 (41)	0 (0)	5 (1)	31.42 (11)	0 (0)	31.91 (15)	40 (12)	0 (0)	0 (0)	40 (2)	0 (0)
Surgical interventions											
Steroid injections	6.17 (11)	12.5 (1)	0 (0)	5.71 (2)	0 (0)	6.38 (3)	13.3 (4)	33.3 (1)	0 (0)	0 (0)	0 (0)
Botulinum toxin injections	4.49 (8)	0 (0)	10 (2)	11.42 (4)	0 (0)	2.12 (1)	3.33 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Arthroscopy	0.56 (1)	0 (0)	0 (0)	0 (0)	0 (0)	2.12 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Arthrocentesis	16.29 (29)	0 (0)	5 (1)	5.71 (2)	0 (0)	21.27 (10)	40 (12)	33.3 (1)	16.6 (1)	40 (2)	0 (0)
Eminectomy	7.86 (14)	0 (0)	0 (0)	2.85 (1)	0 (0)	6.38 (3)	30 (9)	0 (0)	0 (0)	20 (1)	0 (0)
Dental interventions											
Tooth extractions	1.12 (2)	0 (0)	0 (0)	2.85 (1)	0 (0)	3.33 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Orthodontics	1.12 (2)	0 (0)	0 (0)	2.85 (1)	0 (0)	3.33 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Avoidance of ADLs											
Avoidance of eating	85.39 (152)	87.5 (7)	100 (20)	74.28 (26)	100 (3)	89.36 (42)	86.6 (26)	100 (3)	50 (3)	100 (5)	80.95 (17)
Avoidance of talking	25.28 (45)	0 (0)	0 (0)	40 (14)	0 (0)	36.17 (17)	30 (9)	0 (0)	0 (0)	40 (2)	14.28 (3)
Avoidance of singing	21.92 (39)	12.5 (1)	0 (0)	31.42 (11)	0 (0)	31.91 (15)	30 (9)	0 (0)	0 (0)	40 (2)	4.76 (1)
Psychological interventions											
Cognitive behavior treatment	6.17 (11)	0 (0)	0 (0)	5.71 (2)	0 (0)	4.25 (2)	16.66 (5)	0 (0)	0 (0)	40 (2)	0 (0)
Relaxation techniques (eg, music, meditation)	17.97 (32)	37.5 (3)	0 (0)	14.28 (5)	0 (0)	23.4 (11)	23.3 (7)	33.3 (1)	0 (0)	40 (2)	14.28 (3)
Alternative therapies											
Craniosacral therapy	1.12 (2)	0 (0)	0 (0)	0 (0)	0 (0)	4.25 (2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Massage	35.39 (63)	37.5 (3)	35 (7)	28.57 (10)	0 (0)	36.17 (17)	50 (15)	66.6 (2)	16.6 (1)	80 (4)	19.04 (4)
Dry needling	1.68 (3)	0 (0)	0 (0)	2.85 (1)	0 (0)	2.12 (1)	3.33 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Homeopathy	3.37 (6)	12.5 (1)	5 (1)	5.71 (2)	0 (0)	4.25 (2)	3.33 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Chiropractic therapy	3.37 (6)	0 (0)	0 (0)	11.42 (4)	0 (0)	2.12 (1)	3.3 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Aromatherapy	2.8 (5)	0 (0)	0 (0)	5.71 (2)	0 (0)	4.25 (2)	3.3 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Osteopathy	1.12 (2)	0 (0)	0 (0)	2.85 (1)	0 (0)	2.12 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Reiki	1.68 (3)	0 (0)	0 (0)	5.71 (2)	0 (0)	2.12 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Clove oil	0.5 (1)	0 (0)	0 (0)	2.85 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Recreational substances											
Alcohol	1.12 (2)	0 (0)	5 (1)	0 (0)	0 (0)	0 (0)	3.3 (1)	0 (0)	0 (0)	0 (0)	0 (0)
Marijuana	0.5 (1)	0 (0)	0 (0)	2.85 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

Table 5. Cont'd

Other Management Techniques	Overall Sample	Arthralgia	Myalgia	MFP	Headache Attributed to TMD	DDWR	DDWOR	DJD	RA	Subluxation	Unknown
Physiotherapy	7.3 (13)	12.5 (1)	5 (1)	5.71 (2)	0 (0)	12.76 (6)	6.6 (2)	0 (0)	0 (0)	20 (1)	0 (0)
Physical exercise	5.05 (9)	0 (0)	0 (0)	5.71 (2)	0 (0)	10.63 (5)	3.33 (1)	0 (0)	0 (0)	0 (0)	4.76 (1)

Data presented as % (n).

Abbreviations: ADLs, activities of daily living; DDWOR, disc displacement without reduction; DDWR, disc displacement with reduction; DJD, degenerative joint disease; MFP, myofascial pain disorder; RA, rheumatoid arthritis; TMD, temporomandibular disorder.

drinking, and swallowing. In addition, we have provided a snapshot of the current management of TMD-related OD within Irish specialist care centers. This demonstrated that management in this context is highly variable, with the use of both OD-specific and non–OD-specific techniques reported, and poly-modal intervention programs commonly observed. Therefore, to the best of our knowledge, the present research represents the first comprehensive description of a previously unexplored condition and has also documented the range of interventions of which these individuals typically avail.

High levels of eating, drinking, and swallowing difficulties associated with TMDs were identified in our sample. The epidemiologic findings of the present study differ from those previously reported, with regard to the greater prevalence estimates and the broader range of OD symptoms associated with TMD reported by the patients. This lack of concordance with previous results might have resulted from the dedicated focus of our study on specific TMD-related issues and the use of a cohort-specific assessment tool for data collection, both of which have not been featured in previously reported studies. Although broad OD-related symptoms have previously been documented (eg, masticatory impairments), the present study represents the first comprehensive description of the subdomains of physical and psychosocial impairments. For example, within the broad domain of mastication, subdifficulties such as masticatory pain or fatigue were frequently reported, despite previous limited research attention to these symptoms. In addition, although previously unreported,[10,11] many participants in our study identified both weight loss and weight gain as distressing key characteristics of TMD-related OD. Almost one half of the participants reported anxiety, embarrassment, and subsequent social withdrawal because of TMD-related OD, despite a lack of exploration of OD-related psychosocial difficulties in previous investigations of patients with TMDs. This new epidemiologic information will theoretically be beneficial to the production of a standardized nomenclature and case definition of TMD-related OD. Clinically, this might also motivate the subsequent design of specific remediation plans and the future construction of multidisciplinary team (MDT) networks, which are inclusive of a range of professionals with expertise in the treatment of the physical and/or psychosocial impairments associated with OD and/or TMDs (eg, speech and language therapist, clinical nutritionist, psychologist) to improve care delivery.

Recently, research has advocated the provision of poly-modal TMD intervention programs to account for the multifactorial etiology of these conditions.[20-22] As discussed, the concurrent use of poly-modal management techniques, including a range of OD-

specific and non–OD-specific methods, were reported by most participants in our study (93%). However, the data gathered did not differentiate among the interventions recommended or implemented by the clinicians working at recruitment sites, those recommended by other clinicians who had treated the patients during the course of their OD experience, and those the patients had researched independently and self-prescribed. It has been documented internationally that patients experiencing TMDs typically demonstrate high levels of reliance on healthcare services, with reports of cross-discipline "doctor shopping" in an effort to gain relief from the chronic pain and dysfunction.[25] However, information regarding the Irish realization of this phenomenon was previously unavailable. The findings of the present study have demonstrated that this high level of cross-discipline treatment seeking might be elevated in patients experiencing associated OD owing to the added distress and impairment incurred. This hypothesized behavior might be reflected in the broad range of concurrently used disparate interventions reported in the present study. These interventions often had conflicting treatment objectives and diverse levels of supporting evidence and OD specificity. This could, at best, lead to limited clinical outcomes and, at worst, result in potentially adverse events. Within the selected Irish recruitment sites, the inclusion of OD specialists in the treatment of patients with conditions affecting the head, neck, and orofacial region has been primarily restricted to oncologic patients, in contrast to international practice in this field. This has restricted the ability of OD specialist clinicians to contribute positively to effective holistic management of orofacial pain conditions, with potential effects on clinical outcomes and patient recovery. Therefore, inclusive MDT structures for the management of TMD-related OD should be created within both national and international contexts to promote the collaborative communication of assessment findings, treatment goals, and interventions recommended. In addition, the findings of our study might act as motivation for the design of specific and effective treatment programs for TMD-related OD and the creation of dedicated care pathways for patients experiencing these conditions.

STUDY LIMITATIONS

The main limitation of the present study was that treatment-seeking participants presenting to national specialist centers of care for the management of TMD-related symptoms and signs were evaluated. As such, our patient sample might be potentially represented by individuals with more severe difficulties than those attending general practices for management or those self-managing their difficulties within the community population. Therefore, future studies are needed to investigate the prevalence and nature of TMD-related OD in diverse cohorts to ensure that our results are representative.

RECOMMENDATIONS

Future research is needed to validate the TEDSS using representative samples to assess its sensitivity and specificity and to gather data regarding normative score profiles. Similarly, future investigations are needed using both subjective and objective assessment tools to further improve our understanding of TMD-related OD. Finally, the expansion of typical MDT networks to include professionals with expertise in OD management is also advocated to improve care delivery and outcomes.

In conclusion, the results of the present study have highlighted that the signs and symptoms of OD are frequently reported by adults with TMDs and has provided a snapshot of the varied management techniques used in an Irish clinical context to alleviate symptoms of TMD-related OD. In addition, avenues for future clinical development have been suggested, with development of a screening assessment dedicated for use in this patient group.

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APPENDIX 1.
Research Questionnaire:

Age: _____	Gender: __Male __ Female

have you ever experienced any of the following?

Characteristic	Response:	
Facial trauma (eg, broken jaw)	Yes: _____	No: _____
Cancer of the head and neck region	Yes: _____	No: _____
Congenital difficulties of the facial region (eg, cleft palate)	Yes: _____	No: _____
Neurologic difficulties affecting the facial region (eg, stroke)	Yes: _____	No: _____

If you answered yes to any of the above questions, please proceed to the end of the survey.

Cause of Jaw Joint Dysfunction:

Please select the cause of your jaw problems from the list below by ticking the correct box:

Classification of Jaw Joint Problem	Response:
Pain disorders	
Arthralgia	: _____
Myalgia	: _____
Myofascial pain	: _____
Headache attributed to temporomandibular disorder	: _____
Joint disorders	
Disc displacement with reduction	: _____
Disc displacement without reduction	: _____
Degenerative joint disease	: _____
Rheumatoid arthritis	: _____
Subluxation	: _____
Other (please describe)	: _____
Unknown	: _____

Symptoms of Jaw Joint Dysfunction:

Please select the symptoms you have experienced as a result of your jaw joint problem from the list below:

Symptom	Response:	
Difficulty swallowing	Yes: _____	No: _____
Difficulty drinking	Yes: _____	No: _____
Difficulty chewing hard/ crunchy food	Yes: _____	No: _____
Difficulty chewing soft food	Yes: _____	No: _____
Difficulty eating food that requires little/no chewing	Yes: _____	No: _____
Pain on chewing	Yes: _____	No: _____
Tiredness on chewing	Yes: _____	No: _____
Weight loss due to difficulties with eating and drinking	Yes: _____	No: _____
Changes in your diet due to difficulties with eating and drinking	Yes: _____	No: _____
Other (please describe): _____		

Management of Eating, Drinking, and Swallowing Problems caused by Jaw Joint Dysfunction:

Please select the methods you have used to help manage any eating, drinking, and/or swallowing problems caused by your jaw joint problem from the list below:

Method of Management	Response:	
Diet modification (eg, soft or liquidized food)	Yes: _____	No: _____
Pain relief medication	Yes: _____	No: _____
Adapted utensils (eg, straws, special cups, spoons, or bottles)	Yes: _____	No: _____
Oral splints	Yes: _____	No: _____
Acupuncture	Yes: _____	No: _____
Exercises	Yes: _____	No: _____
Other (please describe): _____		

Appendix 11: Ethical Approval: The Prevalence, Nature, and Management of Eating and Swallowing problems in Adults with Temporomandibular Disorders: Findings from an Irish Cohort

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Dublin Dental University Hospital
Trinity College Dublin
Lincoln Place
Dublin 2.

09th May 2016

Re: The prevalence and nature of oropharyngeal dysphagia experienced by adults presenting with temporomandibular disorders

REC Reference: 2016 - 05 Chairman's action (1)
(Please quote reference on all correspondence)

Dear Ms. Gilheaney,

Thank you for your recent application to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above named study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed this application and grants ethical approval for it to proceed.

The following documents reviewed and/or approved:

- A signed copy of the application form and the proposal
- Applicant checklist
- Appendices to include PIL and Questionnaire
- Proof of payment
- Remittance form
- Signature page

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

Appendix 12: The Temporomandibular Disorder Eating, Drinking, and Swallowing Scale: The Prevalence, Nature, and Management of Eating and Swallowing problems in Adults with Temporomandibular Disorders: Findings from an Irish Cohort

Trinity College Dublin

Jaw Joint Function Questionnaire

Introduction

I am Órla Gilheaney, a Ph.D. student studying in the Department of Clinical Speech and Language Studies, Trinity College Dublin.

I am investigating how frequent eating and swallowing problems are in adults with a range of jaw joint problems. As someone who has experienced jaw problems, I would like to invite you to take part in this research by completing this survey. This survey will take approximately five minutes to complete and has been approved by the Research Ethics Committee.

Your involvement in the study is voluntary and all the data in the surveys completed will be anonymous. No identifiable data will be collected and all completed surveys will be compiled together and analysed as a group. If you do not wish to take part, this decision will not impact on the standard of care which you receive in this clinic. If you have any questions or concerns, please contact me by email or postal address provided below.

Kindest Regards,

Órla Gilheaney

Ph.D. Student,

Department of Clinical Speech and Language Studies,

Trinity College Dublin.

+353 876213244

Gilheano@tcd.ie.

Joint Questionnaire

Age: _____ **Gender:** __Male __ Female

Have you ever experienced any of the following?

Characteristic	**Response:**	
Facial trauma (e.g.: broken jaw)	Yes: _____	No: _____
Cancer of the head and neck region	Yes: _____	No: _____
Congenital difficulties of the facial region (e.g.: cleft palate)	Yes: _____	No: _____
Neurological difficulties affecting the facial region (e.g.: stroke)	Yes: _____	No: _____

If you answered yes to any of the above question, please proceed to the end of the survey.

Symptoms of Jaw Problem:

Please select the symptoms of your jaw problems from the list below by ticking the correct box:

Classification of Jaw Joint Problem		**Response:**
Pain Disorders	Arthalgia	: _____
	Myalgia	: _____
	Myofascial pain	: _____
	Headache attributed to temporomandibular disorder	: _____
Joint Disorders	Disc displacement with reduction	: _____
	Disc displacement without reduction	: _____
	Degenerative joint disease	: _____
	Rheumatoid arthritis	: _____
	Subluxation	: _____
Other (Please describe)		: _____
Unknown		: _____

Symptoms of Eating and Swallowing Problems:

Please select the eating and swallowing problems which you have experienced as a result of your jaw problem from the list below:

Symptom	**Response:**	
Difficulty swallowing	Yes: _____	No: _____
Difficulty drinking	Yes: _____	No: _____
Difficulty chewing hard/crunchy food	Yes: _____	No: _____
Difficulty chewing soft food	Yes: _____	No: _____
Difficulty eating food that requires little/no chewing	Yes: _____	No: _____
Pain on chewing	Yes: _____	No: _____
Tiredness on chewing	Yes: _____	No: _____
Weight loss due to difficulties with eating and swallowing	Yes: _____	No: _____
Changes in your diet due to difficulties with eating and swallowing	Yes: _____	No: _____
Other (Please describe): _____		

Management of Eating and Swallowing Problems caused by Jaw Dysfunction:

Please select the methods which you have used to help manage any eating and swallowing problems caused by your jaw problem from the list below:

Method of Management	**Response:**	
Diet modification (e.g.: soft or liquidised food, etc.)	Yes: _____	No: _____
Pain relief medication	Yes: _____	No: _____
Adapted utensils (e.g.: straws, special cups, spoons or bottles, etc.)	Yes: _____	No: _____
Oral splints	Yes: _____	No: _____
Acupuncture	Yes: _____	No: _____
Exercises	Yes: _____	No: _____
Other (Please describe): _____		

Appendix 13: Participant Information Leaflet: The Prevalence, Nature, and Management of Eating and Swallowing problems in Adults with Temporomandibular Disorders: Findings from an Irish Cohort

Trinity College Dublin

Title of Study:

The Prevalence, Nature, and Management of Oral Stage Dysphagia in Adults with Temporomandibular Disorders: Findings from an Irish Cohort.

Introduction:

I am Órla Gilheaney, a Ph.D. student studying in the Department of Clinical Speech and Language Studies, Trinity College Dublin. I am conducting research on eating, drinking, and swallowing problems related to difficulties with the temporomandibular/jaw joint. Temporomandibular/jaw joint problems can restrict the movement of your jaw, cause jaw pain, jaw tiredness, and make it difficult to eat and drink. Little is known about how many people are affected in this way by jaw problems. If researchers knew how many people had these problems, and how these problems affect their daily lives, appropriate and effective treatments could be developed. I am conducting this research is to find the frequency of eating and swallowing difficulties in adults with jaw problems, and to understand the nature of these problems. I would like to invite you to take part in this research.

Procedures:

We are inviting all adults with jaw problems who attend this clinic to complete an anonymous survey. You are eligible to take part if you are:

- 18 years of age or over,
- experiencing jaw joint-related pain and/or movement problems,
- attending the DDUH or SJH during the study period which begins in July 2016.

This brief survey asks questions about the cause and symptoms of your jaw problem. You will also be asked questions about how you manage your jaw problems. This survey will take a maximum of five minutes to complete. No identifying information is sought.

If you wish, you can take the survey home and complete it in your own time. I will provide you with a stamped addressed envelope if you wish to do this. When the survey is completed you can place it in the sealed box positioned by the Reception desk.

Benefits:

This study potentially can provide some information about the number of people with eating and swallowing difficulties caused by jaw joint problems. This study may also be the first step in developing effective treatments for these difficulties.

Risks:

By taking part in this research study, there is no further personal or medical risk than if you were not to participate.

Exclusion from Participation:

You are not eligible to participate if your jaw problems are associated with:

- Facial trauma (e.g.: broken jaw),
- Cancer (or treatment for cancer) of the head and neck region,
- Congenital difficulties affecting the facial area,
- Neurological problems in the facial area (e.g.: stroke, facial nerve injury).

Confidentiality:

All information collected will be anonymous. No identifying information will be collected.

Compensation:

Your doctors are covered by standard medical malpractice insurance. Nothing in this document restricts or curtails your rights.

Voluntary Participation

You have volunteered to participate in this study. You may quit at any time. If you decide not to participate, or if you quit, you will not be penalised and will not give up any benefits which you had before entering the study.

Stopping the Study:

You understand that we or your doctor may stop your participation in the study at any time without your consent.

Permission:

This survey has been approved by the Research Ethics Committee of the DDUH and SJH.

Reimbursements:

No monetary reimbursement will be provided for participation in this survey.

Further Information:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from the primary investigator, Órla Gilheaney, who can be contacted at the details below. If the researcher learns of important new information that might affect your desire to remain in the study, she will tell you.

Name: Órla Gilheaney

Address: 7-9 South Leinster Street, Dublin 2

Phone number: +353 876213244

Email address: Gilheano@tcd.ie

Please tick this box if you consent to completing this survey ☐

Appendix 14: Ethical Approval: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

THE ADELAIDE & MEATH HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND
TELEPHONE +353 1 4142000

Ms. Orla Gilheaney
Department of Clinical Speech and Language Studies
6-9 South Leinster Street
Trinity College Dublin
Dublin 2

7th February 2017

Re: The prevalence and nature of oropharyngeal dysphagia in adults presenting with temporomandibular disorders

REC Reference: 2017-02 Chairman's Action (2)
(Please quote reference on all correspondence)

Dear Ms. Gilheaney,

The REC is in receipt of your recent request to SJH/AMNCH Research Ethics Committee in which you queried ethical approval for the above named study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed your correspondence and granted ethical approval for this study.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.

Appendix 15: Participant Information Leaflet: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Trinity College Dublin

Title of Study:

Oral Stage Dysphagia in adults presenting with Temporomandibular Disorders.

Introduction

I am Órla Gilheaney, a Ph.D. student studying in the Department of Clinical Speech and Language Studies, Trinity College Dublin. I am conducting research on eating and swallowing problems related to difficulties with the temporomandibular/jaw joint. Temporomandibular/jaw joint problems can restrict the movement of your jaw, cause jaw pain, jaw tiredness, and make it difficult to eat and drink. Little is known about how many people are affected in this way by jaw problems. If researchers knew how many people had these problems, and how these problems affect their daily lives, appropriate and effective treatments could be developed. I am conducting this research to find out how common eating and swallowing difficulties are in adults with jaw problems, and to understand the nature of these problems. I would like to invite you to take part in this research.

Procedures:

We are inviting all adults with jaw problems who attend this clinic to participate in this study. You are eligible to take part if you are:

- 18 years of age or over,
- Experiencing jaw joint pain and/or movement problems,
- Attending this clinic during the study period which begins in March 2017.

This study involves the completion of brief questionnaires about the symptoms of your jaw problem and what information you would like to have about your difficulties. You will also be asked to participate in a brief examination of your jaw, and to complete a chewing task.

Benefits:

This study potentially can provide some information about the number of people with eating and swallowing difficulties caused by jaw joint problems. This study may also be the first step in developing effective treatments for these difficulties. The research team intend to use the data about the information that you would like to have to develop an educational booklet about temporomandibular/jaw joint problems and difficulties in eating and swallowing.

Risks:

By taking part in this research study, there is no further personal or medical risk than if you were not to participate.

Exclusion from Participation:

You are not eligible to participate if your jaw problems are associated with:

- Facial trauma (e.g.: broken jaw),
- Cancer (or treatment for cancer) in the head and neck region,
- Congenital difficulties affecting the facial area,
- Neurological problems in the facial area (e.g: Bell's palsy, stroke).

Confidentiality:

All information collected will be anonymously coded and identifiable information will be removed immediately.

Compensation:

Your doctor is covered by standard medical malpractice insurance. Nothing in this document restricts or curtails your rights.

Voluntary Participation

You have volunteered to participate in this study. You may quit at any time. If you decide not to participate, or if you quit, you will not be penalised and will not give up any benefits which you had before entering the study.

Stopping the study:

You understand that your doctor may stop your participation in the study at any time without your consent.

Permission:

This survey has been approved by the Research Ethics Committee of St. James's Hospital.

Reimbursements:

No monetary reimbursement will be provided for participation in this survey.

Further Information:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from the primary investigator, Órla Gilheaney, who can be contacted at the details below. If the researcher learns of important new information that might affect your desire to remain in the study, she will tell you.

Address: 7-9 South Leinster Street, Dublin 2
Phone number: +353 876213244
Email address: Gilheano@tcd.ie

Appendix 16: Informed Consent Form: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Trinity College Dublin

This Informed Consent Form is for adult men and women who attend this clinic and who we are inviting to participate in research investigating the prevalence and nature of eating and swallowing problems caused by temporomandibular/jaw joint disorders.

Title of Research Study:

Oral Stage Dysphagia in adults presenting with Temporomandibular Disorders.

This study and this consent form have been explained to me. The researcher has answered all my questions to my satisfaction. I believe I understand what will happen if I agree to be part of this study. I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I have received a copy of this agreement and I understand that, if there is a sponsoring company, a signed copy will be sent to that sponsor.

Print Name of Participant:

_____
Signature of Participant:

_____
Date (Day/month/year):

_____
Date on which the participant was first furnished with this form:

_____
Where the participant is incapable of comprehending the nature, significance and scope of the consent required, the form must be signed by a person competent to give consent to his or her participation in the research study (other than a person who applied to undertake or conduct the study).

NAME OF CONSENTOR: _____
SIGNATURE: _____
RELATION TO PARTICIPANT: _____

Where the participant is capable of comprehending the nature, significance and scope of the consent required, but is unable to sign written consent, signatures of two witnesses present when consent was given by the participant.

NAME OF FIRST WITNESS: _____
SIGNATURE: _____

NAME OF SECOND WITNESS: _____
SIGNATURE: _____

Statement of investigator's responsibility:

I have explained the nature, purpose, procedures, benefits, risks of, or alternatives to, this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Researcher's signature: _____
Date: _____

Appendix 17: Axis I Assessment of the DC/TMD: Symptom Questionnaire: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Symptom Questionnaire

1.	Have you ever had pain in your jaw, temple, in the ear, or in front of the ear on either side?	No ☐	Yes ☐
	If you answered NO, then skip to Question 5.		
2.	How many years or months ago did your pain in the jaw, temple, in the ear, or in front of the ear first begin?	_____years	_____months
3.	In the last 30 days, which of the following best describes any pain in your jaw, temple, in the ear, or in front of the ear on either side? Select ONE response.	☐ No pain ☐ Pain comes and goes ☐ Pain is always present	
	If you answered NO to Question 3, then skip to Question 5.		

4. In the last 30 days, did the following activities change any pain (that is, make it better or make it worse) in your jaw, temple, in the ear, or in front of the ear on either side?

		No	Yes
A.	Chewing hard or tough food	☐	☐
B.	Opening your mouth, or moving your jaw forward or to the side	☐	☐
C.	Jaw habits such as holding teeth together, clenching/grinding teeth, or chewing gum	☐	☐
D.	Other jaw activities such as talking, kissing, or yawning	☐	☐

HEADACHE

5.	In the last 30 days, have you had any headaches that included the temple areas of your head?	No ☐	Yes ☐
	If you answered NO to Question 5, then skip to Question 8.		
6.	How many years or months ago did your temple headache first begin?	_____years	_____months

7. In the last 30 days, did the following activities change any headache (that is, make it better or make it worse) in your temple area on either side?

		No	Yes
A.	Chewing hard or tough food	☐	☐
B.	Opening your mouth, or moving your jaw forward or to the side	☐	☐
C.	Jaw habits such as holding teeth together, clenching/grinding, or chewing gum	☐	☐
D.	Other jaw activities such as talking, kissing, or yawning	☐	☐

JAW JOINT NOISES				Office use		
8.	In the last 30 days, have you had any jaw joint noise(s) when you moved or used your jaw?	No ☐	Yes ☐	R ☐	L ☐	DNK ☐
CLOSED LOCKING OF THE JAW						
9.	Have you ever had your jaw lock or catch, even for a moment, so that it would not open ALL THE WAY? **If you answered NO to Question 9 then skip to Question 13.**	☐	☐	☐	☐	☐
10.	Was your jaw lock or catch severe enough to limit your jaw opening and interfere with your ability to eat?	☐	☐	☐	☐	☐
11.	In the last 30 days, did your jaw lock so you could not open ALL THE WAY, even for a moment, and then unlock so you could open ALL THE WAY? **If you answered NO to Question 11 then skip to Question 13.**	☐	☐	☐	☐	☐
12.	Is your jaw currently locked or limited so that your jaw will not open ALL THE WAY?	☐	☐	☐	☐	☐
OPEN LOCKING OF THE JAW						
13.	In the last 30 days, when you opened your mouth wide, did your jaw lock or catch even for a moment such that you could not close it from this wide open position? **If you answered NO to Question 13 then you are finished.**	☐	☐	☐	☐	☐
14.	In the last 30 days, when you jaw locked or caught wide open, did you have to do something to get it to close including resting, moving, pushing, or maneuvering it?	☐	☐	☐	☐	☐

Appendix 18: The Jaw Functional Limitation Scale: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Jaw Functional Limitation Scale – 8

For each of the items below, please indicate the level of limitation **during the last month**. If the activity has been completely avoided because it is too difficult, then circle '10'. If you avoid an activity for reasons other than pain or difficulty, leave the item blank.

		No limitation										Severe Limitation
1.	Chew tough food	0	1	2	3	4	5	6	7	8	9	10
2.	Chew chicken (e.g., prepared in oven)	0	1	2	3	4	5	6	7	8	9	10
3.	Eat soft food requiring no chewing (e.g., mashed potatoes, apple sauce, pudding, pureed food)	0	1	2	3	4	5	6	7	8	9	10
4.	Open wide enough to drink from a cup	0	1	2	3	4	5	6	7	8	9	10
5.	Swallow	0	1	2	3	4	5	6	7	8	9	10
6.	Yawn	0	1	2	3	4	5	6	7	8	9	10
7.	Talk	0	1	2	3	4	5	6	7	8	9	10
8.	Smile	0	1	2	3	4	5	6	7	8	9	10

Appendix 19: The Graded Chronic Pain Scale: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

The Graded Chronic Pain Scale

1. On how many days in the **last 6 months** have you had facial pain? _____ Days

2. How would you rate your facial pain **RIGHT NOW?** Use a scale from 0 to 10, where 0 is "no pain" and 10 is "pain as bad as could be".

No pain — Pain as bad as could be

0 1 2 3 4 5 6 7 8 9 10

3. In the LAST 30 DAYS, how would you rate your **WORST** facial pain? Use the same scale, where 0 is "no pain" and 10 is "pain as bad as could be".

No pain — Pain as bad as could be

0 1 2 3 4 5 6 7 8 9 10

4. In the LAST 30 DAYS, **ON AVERAGE**, how would you rate your facial pain? Use the same scale, where 0 is "no pain" and 10 is "pain as bad as could be". [That is, *your usual pain* at times you were in pain.]

No pain — Pain as bad as could be

0 1 2 3 4 5 6 7 8 9 10

5. In the LAST 30 DAYS, how many days did your facial pain keep you from doing your **USUAL ACTIVITIES** like work, school, or housework? (every day = 30 days)

_____ Days

6. In the LAST 30 DAYS, how much has facial pain interfered with your **DAILY ACTIVITIES**? Use a 0-10 scale, where 0 is "no interference: and 10 is "unable to carry on any activities".

No interference — Unable to carry on any activities

0 1 2 3 4 5 6 7 8 9 10

7. In the LAST 30 DAYS, how much has facial pain interfered with your **RECREATIONAL, SOCIAL AND FAMILY ACTIVITIES**? Use the same scale, where 0 is "no interference: and 10 is "unable to carry on any activities".

No interference — Unable to carry on any activities

0 1 2 3 4 5 6 7 8 9 10

8. In the LAST 30 DAYS, how much has facial pain interfered with your **ABILITY TO WORK**, including housework? Use the same scale, where 0 is "no interference: and 10 is "unable to carry on any activities".

No interference — Unable to carry on any activities

0 1 2 3 4 5 6 7 8 9 10

Appendix 20: The Patient Health Questionnaire-4: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

The Patient Health Questionnaire-4

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems? *(Use "✓" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Little interest or pleasure in doing things	0	1	2	3
4. Feeling down, depressed, or hopeless	0	1	2	3

Appendix 21: The Oral Behaviour Checklist: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

The Oral Behavior Checklist

How often do you do each of the following activities, based on **the last month**? If the frequency of the activity varies, choose the higher option. Please place a (√) response for each item and do not skip any items.

	Activities During Sleep	None of the time	< 1 Night /Month	1-3 Nights /Month	1-3 Nights /Week	4-7 Nights/ Week
1	Clench or grind teeth **when asleep**, based on any information you may have	☐	☐	☐	☐	☐
2	Sleep in a position that puts pressure on the jaw (for example, on stomach, on the side)	☐	☐	☐	☐	☐
	Activities During Waking Hours	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
3	Grind teeth together **during waking hours**	☐	☐	☐	☐	☐
4	Clench teeth together **during waking hours**	☐	☐	☐	☐	☐
5	Press, touch, or hold teeth together other than while eating (that is, contact between upper and lower teeth)	☐	☐	☐	☐	☐
6	Hold, tighten, or tense muscles without clenching or bringing teeth together	☐	☐	☐	☐	☐
7	Hold or jut jaw forward or to the side	☐	☐	☐	☐	☐
8	Press tongue forcibly against teeth	☐	☐	☐	☐	☐
9	Place tongue between teeth	☐	☐	☐	☐	☐
10	Bite, chew, or play with your tongue, cheeks or lips	☐	☐	☐	☐	☐
11	Hold jaw in rigid or tense position, such as to brace or protect the jaw	☐	☐	☐	☐	☐
12	Hold between the teeth or bite objects such as hair, pipe, pencil, pens, fingers, fingernails, etc	☐	☐	☐	☐	☐
13	Use chewing gum	☐	☐	☐	☐	☐
14	Play musical instrument that involves use of mouth or jaw (for example, woodwind, brass, string instruments)	☐	☐	☐	☐	☐
15	Lean with your hand on the jaw, such as cupping or resting the chin in the hand	☐	☐	☐	☐	☐
16	Chew food on one side only	☐	☐	☐	☐	☐
17	Eating between meals (that is, food that requires chewing)	☐	☐	☐	☐	☐
18	Sustained talking (for example, teaching, sales, customer service)	☐	☐	☐	☐	☐
19	Singing	☐	☐	☐	☐	☐

Appendix 22: The Dysphagia Handicap Index: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Participant ID number: _____ **Date of completion: _____**

		Never	Sometimes	Always
1P.	I cough when I drink liquids.			
2P.	I cough when I eat solid food.			
3P.	My mouth is dry.			
4P.	I need to drink fluids to wash food down.			
5P.	I've lost weight because of my swallowing problem.			
1F.	I avoid some foods because of my swallowing problem.			
2F.	I have changed the way I swallow to make it easier to eat.			
1E.	I'm embarrassed to eat in public.			
3F.	It takes me longer to eat a meal than it used to.			
4F.	I eat smaller meals more often due to my swallowing problem.			
6P.	I have to swallow again before food will go down.			
2E.	I feel depressed because I can't eat what I want.			
3E.	I don't enjoy eating as much as I used to.			
5F.	I don't socialize as much due to my swallowing problem.			
6F.	I avoid eating because of my swallowing problem.			
7F.	I eat less because of my swallowing problem.			
4E.	I am nervous because of my swallowing problem.			
5E.	I feel handicapped because of my swallowing problem.			
6E.	I get angry at myself because of my swallowing problem.			
7P.	I choke when I take my medication.			
7E.	I'm afraid that I'll choke and stop breathing because of my swallowing problem.			
8F.	I must eat another way (e.g., feeding tube) because of my swallowing problem.			
9F.	I've changed my diet due to my swallowing problem.			
8P.	I feel a strangling sensation when I swallow.			
9P.	I cough up food after I swallow.			

1	2	3	4	5	6	7
Normal			Moderate		Severe	

Please circle the number that matches the severity of your swallowing difficulty (1 = no difficulty at all; 4 = somewhat of a problem; 7 = the worse problem you could have)

Appendix 23: The DC/TMD Examination Tool: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

DC/TMD Examination

DC/TMD Examination Form

Date filled out (mm-dd-yyyy) ___-___-____

Patient _____ Examiner _____

1a. Location of Pain: Last 30 days (Select all that apply)

RIGHT PAIN				LEFT PAIN			
O None	O Temporalis	O Other m muscles	O Non-mast	O None	O Temporalis	O Other m muscles	O Non-mast
	O Masseter	O TMJ	structures		O Masseter	O TMJ	structures

1b. Location of Headache: Last 30 days (Select all that apply)

O None O Temporal O Other O None O Temporal O Other

2. Incisal Relationships **Reference tooth** O FDI #11 O FDI #21 O Other

Horizontal Incisal Overjet O If negative ___ mm Vertical Incisal Overlap O If negative ___ mm Midline Deviation Right O Left O N/A O ___ mm

3. Opening Pattern (Supplemental; Select all that apply)

O Straight O Corrected deviation Uncorrected Deviation: O Right O Left

4. Opening Movements

A. Pain Free Opening ___ mm

B. Maximum Unassisted Opening ___ mm

C. Maximum Assisted Opening ___ mm

D. Terminated? (N) (Y)

RIGHT SIDE				LEFT SIDE			
	Pain	Familiar Pain	Familiar Headache		Pain	Familiar Pain	Familiar Headache
Temporalis	(N) (Y)	(N) (Y)	(N) (Y)	Temporalis	(N) (Y)	(N) (Y)	(N) (Y)
Masseter	(N) (Y)	(N) (Y)		Masseter	(N) (Y)	(N) (Y)	
TMJ	(N) (Y)	(N) (Y)		TMJ	(N) (Y)	(N) (Y)	
Other M Musc	(N) (Y)	(N) (Y)		Other M Musc	(N) (Y)	(N) (Y)	
Non-mast	(N) (Y)	(N) (Y)		Non-mast	(N) (Y)	(N) (Y)	
Temporalis	(N) (Y)	(N) (Y)	(N) (Y)	Temporalis	(N) (Y)	(N) (Y)	(N) (Y)
Masseter	(N) (Y)	(N) (Y)		Masseter	(N) (Y)	(N) (Y)	
TMJ	(N) (Y)	(N) (Y)		TMJ	(N) (Y)	(N) (Y)	
Other M Musc	(N) (Y)	(N) (Y)		Other M Musc	(N) (Y)	(N) (Y)	
Non-mast	(N) (Y)	(N) (Y)		Non-mast	(N) (Y)	(N) (Y)	

5. Lateral and Protrusive Movements

A. Right Lateral ___ mm

B. Left Lateral ___ mm

C. Protrusion ___ mm

O If negative

RIGHT SIDE				LEFT SIDE			
	Pain	Familiar Pain	Familiar Headache		Pain	Familiar Pain	Familiar Headache
Temporalis	(N) (Y)	(N) (Y)	(N) (Y)	Temporalis	(N) (Y)	(N) (Y)	(N) (Y)
Masseter	(N) (Y)	(N) (Y)		Masseter	(N) (Y)	(N) (Y)	
TMJ	(N) (Y)	(N) (Y)		TMJ	(N) (Y)	(N) (Y)	
Other M Musc	(N) (Y)	(N) (Y)		Other M Musc	(N) (Y)	(N) (Y)	
Non-mast	(N) (Y)	(N) (Y)		Non-mast	(N) (Y)	(N) (Y)	
Temporalis	(N) (Y)	(N) (Y)	(N) (Y)	Temporalis	(N) (Y)	(N) (Y)	(N) (Y)
Masseter	(N) (Y)	(N) (Y)		Masseter	(N) (Y)	(N) (Y)	
TMJ	(N) (Y)	(N) (Y)		TMJ	(N) (Y)	(N) (Y)	
Other M Musc	(N) (Y)	(N) (Y)		Other M Musc	(N) (Y)	(N) (Y)	
Non-mast	(N) (Y)	(N) (Y)		Non-mast	(N) (Y)	(N) (Y)	
Temporalis	(N) (Y)	(N) (Y)	(N) (Y)	Temporalis	(N) (Y)	(N) (Y)	(N) (Y)
Masseter	(N) (Y)	(N) (Y)		Masseter	(N) (Y)	(N) (Y)	
TMJ	(N) (Y)	(N) (Y)		TMJ	(N) (Y)	(N) (Y)	
Other M Musc	(N) (Y)	(N) (Y)		Other M Musc	(N) (Y)	(N) (Y)	
Non-mast	(N) (Y)	(N) (Y)		Non-mast	(N) (Y)	(N) (Y)	

6. TMJ Noises During Open & Close Movements

RIGHT TMJ	Examiner		Patient	Pain w/ Click	Familiar Pain
	Open	Close			
Click	N Y	N Y	N Y	N Y	N Y
Crepitus	N Y	N Y	N Y		

LEFT TMJ	Examiner		Patient	Pain w/ Click	Familiar Pain
	Open	Close			
Click	N Y	N Y	N Y	N Y	N Y
Crepitus	N Y	N Y	N Y		

7. TMJ Noises During Lateral & Protrusive Movements

RIGHT TMJ	Examiner	Patient	Pain w/ Click	Familiar Pain
Click	N Y	N Y	N Y	N Y
Crepitus	N Y	N Y		

LEFT TMJ	Examiner	Patient	Pain w/ Click	Familiar Pain
Click	N Y	N Y	N Y	N Y
Crepitus	N Y	N Y		

8. Joint Locking

RIGHT TMJ	Locking	Reduction	
		Patient	Examiner
While Opening	N Y	N Y	N Y
Wide Open Position	N Y	N Y	N Y

LEFT TMJ	Locking	Reduction	
		Patient	Examiner
While Opening	N Y	N Y	N Y
Wide Open Position	N Y	N Y	N Y

9. Muscle & TMJ Pain with Palpation

RIGHT SIDE (1 kg)	Pain	Familiar Pain	Familiar Headache	Referred Pain
Temporalis (posterior)	N Y	N Y	N Y	N Y
Temporalis (middle)	N Y	N Y	N Y	N Y
Temporalis (anterior)	N Y	N Y	N Y	N Y
Masseter (origin)	N Y	N Y		N Y
Masseter (body)	N Y	N Y		N Y
Masseter (insertion)	N Y	N Y		N Y

TMJ	Pain	Familiar Pain	Referred Pain
Lateral pole **(0.5 kg)**	N Y	N Y	N Y
Around lateral pole **(1 kg)**	N Y	N Y	N Y

LEFT SIDE (1 kg)	Pain	Familiar Pain	Familiar Headache	Referred Pain
Temporalis (posterior)	N Y	N Y	N Y	N Y
Temporalis (middle)	N Y	N Y	N Y	N Y
Temporalis (anterior)	N Y	N Y	N Y	N Y
Masseter (origin)	N Y	N Y		N Y
Masseter (body)	N Y	N Y		N Y
Masseter (insertion)	N Y	N Y		N Y

	Pain	Familiar Pain	Referred Pain
Lateral pole **(0.5 kg)**	N Y	N Y	N Y
Around lateral pole **(1 kg)**	N Y	N Y	N Y

10. Supplemental Muscle Pain with Palpation

RIGHT SIDE (0.5 kg)	Pain	Familiar Pain	Referred Pain
Posterior mandibular region	N Y	N Y	N Y
Submandibular region	N Y	N Y	N Y
Lateral pterygoid area	N Y	N Y	N Y
Temporalis tendon	N Y	N Y	N Y

LEFT SIDE (0.5 kg)	Pain	Familiar Pain	Referred Pain
Posterior mandibular region	N Y	N Y	N Y
Submandibular region	N Y	N Y	N Y
Lateral pterygoid area	N Y	N Y	N Y
Temporalis tendon	N Y	N Y	N Y

11. Diagnoses

Pain Disorders	Right TMJ Disorders	Left TMJ Disorders
○ None	○ None	○ None
○ Myalgia	Disc displacement (select one)	Disc displacement (select one)
○ Myofascial pain with referral	○ ...with reduction	○ ...with reduction
○ Right Arthralgia	○ ...with reduction, with intermittent locking	○ ...with reduction, with intermittent locking
○ Left Arthralgia	○ ... without reduction, with limited opening	○ ... without reduction, with limited opening
○ Headache attributed to TMD	○ ... without reduction, without limited opening	○ ... without reduction, without limited opening
	○ Degenerative joint disease	○ Degenerative joint disease
	○ Dislocation	○ Dislocation

12. Comments

Appendix 24: Orofacial Examination Tool: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Participant ID number: _____ **Date of completion: _____**

Oral Status			**Comments**
Dentition:	WNL		
	Decay		
	Missing teeth		
	Dentures present:	Upper:	
		Lower:	

Oral Motor, Respiration, and Phonation									**Comments**
Lips:	Observation at rest:	WNL		Edema	Lesion	Erythema			
	Symmetry:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Range of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Speed of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Strength:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Tone:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Pucker:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Retraction:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Alternating pucker/retraction:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Involuntary movement:	WNL	Chorea	Dystonia	Fasciculations	Myoclonus	Spasms	Tremor	

Tongue:	Observation at rest:	WNL		Edema	Lesion	Erythema			
	Symmetry:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Range of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Speed of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Strength:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Tone:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Protrusion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Retraction:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Lateralization:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Involuntary movement:	WNL	Chorea	Dystonia	Fasciculations	Myoclonus	Spasms	Tremor	

TMJ:	Observation at rest:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Symmetry:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Range of motion:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Speed of motion:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Strength:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Tone:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	

	Protrusion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Retraction:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Lateralization:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Opening:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Closing:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Involuntary movement:	WNL	Chorea	Dystonia	Fasciculations	Myoclonus	Spasms	Tremor	

Soft Palate:	Observation at rest:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Symmetry:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Range of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Speed of motion:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Strength:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Tone:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Elevation:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Sustained elevation:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Alternating elevation/relaxation:	WNL		Mild Impairment	Moderate Impairment	Severe Impairment			
	Involuntary movement:	WNL	Chorea	Dystonia	Fasciculations	Myoclonus	Spasms	Tremor	

Phonation:	GRBAS Scale Rating:	G	R	B	A	S	
	Maximum phonation time:	1.	2.	3.	Average:		
	S/Z ratio:	1.	2.	3.	Average:		

Respiratory Sufficiency and Coordination:	Observation at rest:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	
	Observation in conversation:	WNL	Mild Impairment	Moderate Impairment	Severe Impairment	

Appendix 25: The Test of Masticating and Swallowing Solids: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

The Test of Masticating and Swallowing Solids Data Collection Form

Participant ID number: _____ **Date of completion: _____**

Raw Data:

Cracker number	**1**	**2**
Total number of bites		
Total number of masticatory cycles		
Total number of swallows		
Total time taken for task		

Statistical Analysis:

Cracker number	**1**	**2**	**Average**
Masticatory cycles per bite			
Masticatory cycles per swallow			
Swallows per bite			
Time per masticatory cycle			
Time per swallow			

Appendix 26: Patient Information Needs Survey: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Age:_____ **Gender:**__**Male**__**Female**

Participant number (office use):_____

Please answer the questions below in the space provided:

Question	Response
What information have you received about your TMD and eating and swallowing difficulties?	
Do you feel that you have received enough information about your TMD and eating and swallowing difficulties?	
Do you think an information booklet about your difficulties would be helpful?	
If yes, when would be the best time to receive this information?	
What things would you like to know about?	
Are you particularly worried about anything relating to your TMD?	

How strongly would you rate your need for the information listed below?

Information Statement	This information is most important to me	This information is somewhat important to me	This information is not important to me
The specific medical name of the condition			
The cause of the TMD and eating and swallowing difficulties			
Who typically gets these problems and what are the risk factors			
Information on possible assessments for TMD and eating and swallowing difficulties			
What each assessment specifically investigates			
Information on all the possible treatments			
Possible side effects of different treatments			
How the treatment works			
Post treatment follow-up care			
Self-care strategies that can be done at home to relieve symptoms			
Common coping strategies to help deal with physical and emotional consequences of TMD and eating and swallowing difficulties			
Information on prevention/management of symptom recurrence			
Useful resources and contacts for more information			
Other Information (please specify):			

Appendix 27: Draft Information Booklet: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders

Living well with feeding, eating, drinking, and swallowing difficulties caused by temporomandibular disorders

A guide for patients, carers, and healthcare professionals

Trinity College Dublin
The University of Dublin

OSPIDÉAL DÉADACH BHAILE ÁTHA CLIATH
DUBLIN DENTAL HOSPITAL

- This booklet was written by Órla Gilheaney and Professor Margaret Walshe of the Department of Clinical Speech and Language Studies in Trinity College Dublin, and Professor Leo Stassen of the Dublin Dental University Hospital and St. James's Hospital.

  This booklet should be used as a reference guide for individuals experiencing eating, drinking, and swallowing difficulties caused by jaw/temporomandibular joint disorders.

  Any advice provided here should not replace direct care provided by a multidisciplinary team, and individuals should contact their primary healthcare practitioner with any further queries.

Introduction

- Disorders of the jaw/ temporomandibular joint (TMJ) can make it difficult to eat and drink, and can cause increased risk of pain or tiredness on chewing, choking incidents, and an inability to eat foods which you once typically managed and enjoyed.
- This booklet addresses the nature of temporomandibular disorders, their effect on eating, drinking, and swallowing, and provides the reader with management strategies to help improve common signs and symptoms.

What is the temporomandibular joint?

- The jaw joint is also known as the "temporomandibular joint" (TMJ). This joint connects the lower jaw bone (the mandible), to the skull bone (the temporal bone) on both sides of the skull.
- The TMJ is made up of a disc, bone, articular surfaces, fibrous capsule, synovial fluid, synovial membrane, and ligaments.
- The TMJ is stabilised by muscles that connect to it and controlling its motion.
- The TMJ allows both hinging and gliding movements[1-4].
- The TMJ allows us to open our mouth, speak, breathe, swallow, drink, chew, and show facial expressions[5].

What are temporomandibular disorders?

- Temporomandibular disorder (TMDs) is an umbrella term for a range of disorders characterised by pain and/or dysfunction of the TMJ[6].
- TMDs may develop due to difficulties with:
  - The structure and/or function of the TMJ,
  - The wider jaw musculature system, or
  - The bones and/or cartilage which make up the TMJ[6-9].
- Individuals presenting with TMDs may experience jaw and/or ear and facial pain, headaches, increased risk of choking, difficulties moving the jaw joint, jaw joint sounds, tooth erosion, and difficulties eating, drinking, and swallowing, among other signs and symptoms[10-11].
- The signs and symptoms TMDs vary widely depending on how each person experiences and/or reacts to them[12].

How are TMDs classified?

- TMDs are typically classified into either **pain** or **joint** disorders:
  - **Pain disorders** include pain in the facial muscles which is made worse by movement. Pain disorders include headaches affected by jaw movement.
  - **Joint disorders** include open or closed locking of the jaw joint with limited mouth opening, joint sounds on movement, and jaw dislocation.
- You may experience signs and symptoms of both pain and joint disorders in either/both sides of your TMJ[14].
- Other conditions can also affect the structure and function of the TMJ joint, such as rheumatoid arthritis, systemic lupus erythematosus, or trauma [15].

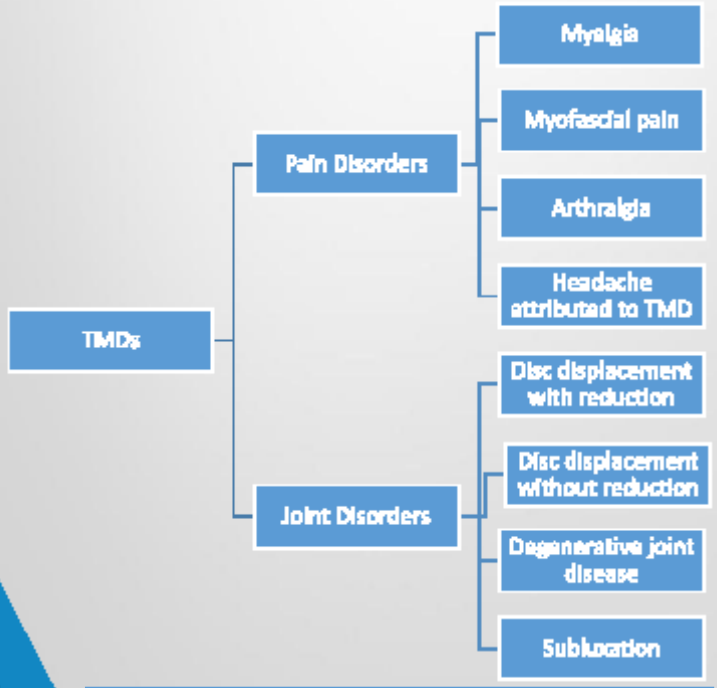


Figure 1: Classification of TMDs

How do TMDs impact on eating drinking and swallowing?

- Eating and drinking are complex skills and require the functioning of 26 muscles and 6 key nerves.
- If one or more of these components are damaged, difficulties with eating, drinking, and swallowing (dysphagia) may develop.
- Typically swallowing is characterised by 3 phases:
  - The oral preparatory and oral phase,
  - The pharyngeal phase, and
  - The oesophageal phase.
- TMDs typically cause difficulties in the oral preparatory and oral phase, with possible problems at the pharyngeal phase.

How do TMDs impact on eating drinking and swallowing?

- The oral phase involves the following:
  - Opening the mouth,
  - Forming a tight seal of the mouth using the lips,
  - Breaking up/chewing the food using the teeth, jaw, and tongue,
  - Forming a manageable portion of food/fluid to safely swallow,
  - Moving the food towards the back of the tongue in order to swallow the food/fluid[16-17].

- If you have TMD problems you may experience the following:
  - Difficulty opening the mouth,
  - Loss of food/fluid from your mouth while eating/drinking/chewing,
  - Severe pain and fatigue on chewing,
  - Dislocation/locking of the TMJ on opening, closing, and chewing,
  - Difficulty forming small and manageable food/liquid portions to safely swallow without risk of choking,
  - A choking/gagging sensation in your throat caused by trying to swallow pieces of food that are too large,
  - Inability to eat foods that you typically managed and enjoyed before you experienced TMJ difficulties.

How are swallowing disorders related to TMDs diagnosed?

- TMDs are frequently diagnosed by dental professionals, oral surgeons, or oral and maxillofacial surgeons [18].
- These professionals will carry out an assessment and may detect signs and symptoms of impaired eating, drinking, and swallowing.
- If this happens, they may refer you to a speech and language therapist and/or dietitian for further assessment.
- A speech and language therapist will assess for these signs and symptoms using a combination of the following methods, as needed:
  - **Subjective assessments**: these include examinations of the muscles in your head, neck, mouth, and throat; completion of rating scales about functioning and/or quality of life; mealtime observations; and swallow trials.
  - **Instrumental assessments:** these evaluate swallowing and determine the most appropriate consistency and/or texture for you to eat/drink. These include videofluoroscopy (a swallow x-ray) and fiberoptic endoscopic evaluations of swallowing (scoping techniques which allow the clinician to see inside your nasal, oral, and pharyngeal spaces) [19].
- A **dietitian** will assess your nutritional status, with subsequent diagnosis and treatment of dietary and nutritional problems, where appropriate. Dietitians support you in making healthy and balanced lifestyle, food, and fluid choices [20-21].

Management options for swallowing difficulties related to TMDs

- TMD-related eating, drinking, and swallowing difficulties can be treated using conservative and/or invasive/surgical procedures.
- Conservative management options are usually the first treatments trialled.
- The majority of people with TMDs get symptom relief from these treatments.
- **Conservative management techniques** include:
- Rest and relaxation,
- Exercises,
- Limiting the degree of mouth opening,
- Reducing unhelpful oral habits activities,
- Medication,
- Intra-articular injections (e.g.: steroid injections)
- Diet modifications,
- Mealtime modifications,
- Oral splints, and
- Botulinum toxin injections[22-28].

Rest and relaxation

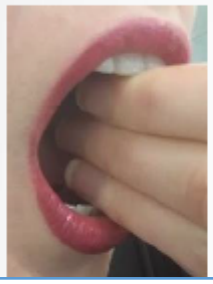
- Tooth grinding/clenching and tension in the oral and facial muscles can increase in response to stressful events. This can cause increased pain and/or tension in the oral and facial muscles. Therefore TMDs can be made worse by stressful life events.
- TMJ pain can also be exacerbated by your response/reaction to stressful life events. This pain can make it difficult to eat and drink normally [24-25].
- Reducing stress in daily life can help to reduce overall body tension and anxiety.
- Reduced tension and anxiety can result in reductions in pain, tension, and fatigue while eating and drinking.

Exercises

- A doctor or dentist may recommend exercises to help improve the way that your jaw opens[26].
- These include range of motion and relaxation exercises.
- These may be recommended after an assessment and the doctor or dentist may instruct you about what exercises to do and how often to do them.

Limit mouth opening

- TMDs can cause limited mouth opening, jaw locking, muscle spasm, and/or pain and fatigue.
- However, it is not recommended to open your mouth wider than 3 fingers.



Picture 1: Mouth opening of 3 fingers

- At any greater distance than this, you are risking subluxation/dislocation.
- It is important to limit mouth opening during tasks such as:
  - Eating,
  - Drinking,
  - Laughing,
  - Singing,
  - Yawning,
  - Shouting.
- You can limit mouth opening by placing a hand/fist under your jaw while doing these activities.
- It is important to be aware of when you open your mouth very wide, and to try remember to limit opening.
- Reduced mouth opening can reduce pain and fatigue in the jaw joint and muscles.

Reducing unhelpful habits

- People experiencing TMDs may engage in many unhelpful oral habits that are damaging to the jaw joint[28]. For example:
  - Teeth grinding or clenching,
  - Nail biting,
  - Biting of pens/pencils,
  - Thumb sucking,
  - Thrusting of the tongue against the teeth,
  - Chewing gum,
  - Constantly biting cheeks and lips,
  - Cupping/ resting the jaws on the hands [29].
- These habits can make your TMD worse and cause significant pain and fatigue which can impair eating and drinking.
- It is important to identify any unhelpful habits which you might have and to try to reduce these.
- The "ABC" technique can be helpful in this process.
- **A (antecedent):** Identify the event/emotion/situation which caused you to feel stressed.
- **B (behaviour):** identify what oral behaviours you engage in (e.g.: nail biting, chin cupping, thumb sucking, etc.).
- **C (consequence):** identify the consequence of this behaviour (e.g.: jaw pain, fatigue, ear pain, etc.).

Medications

- Medications may be prescribed to people experiencing eating, drinking, and swallowing difficulties to reduce pain, discomfort, and muscle tension.
- Medications prescribed for TMDs fall into three broad categories:
  - **Over the counter pain relief and non-steroidal anti-inflammatory drugs (e.g.: Ibuprofen)**
  - **Tricyclic antidepressants:** tricyclic antidepressants (e.g: amitriptyline) are traditionally used to alleviate symptoms of depression, but they can also work to treat chronic pain.
  - **Muscle relaxants:** these may be prescribed for a short period of time to relieve muscular pain and tension caused by TMDs[3a].
- These medications can help relieve pain and discomfort caused by TMDs, and make it more comfortable to chew and swallow food.
- Please consult your oral surgeon or pharmacist for further information.

Intra-articular injections

- For some individuals experiencing TMD-related eating, drinking, and swallowing disorders, intra-articular/joint injections may be recommended.
- These are steroid injections into the TMJ that reduce pain and inflammation.
- These injections are usually recommended for people experiencing TMDs associated with arthritic joint changes.
- A small amount of local anaesthetic is injected into the area before the intra-articular injection is completed. This numbs any pain which may be felt[3a].

Diet modifications

- A speech and language therapist may recommend that you should modify your diet or choose "softer" options.
- A softer diet is recommended to minimize the amount and difficulty of chewing required, to reduce the movement of your TMJ.
- These are several levels of texture modified diets recommended to patients with eating, drinking, and swallowing difficulties , as outlined by the Irish Association of Speech and Language Therapists and the Irish Nutrition and Dietetic Institute:
  - Soft diet,
  - Minced and moist diet,
  - Smooth pureed diet, and
  - Liquidised diet [32].
- Below are descriptions of each of these texture modified diets, with ideas of recommended food and foods to avoid at each prescribed diet level. This list is not exhaustive.

	Texture A – Soft diet
Description	Food may be naturally soft (e.g. ripe banana) or may be cooked/cut to alter its texture
Characteristics	Soft foods can be chewed but not necessarily bitten Minimal cutting required – easily broken up with a fork Food should be moist or served with a sauce or gravy to increase moisture content
Examples of recommended food	Soft sandwiches with very moist fillings Cereals moistened with milk Soft pasta and noodles Well-cooked vegetables, naturally soft fresh fruit pieces Milk, milkshakes, smoothies, smooth puddings, yoghurt, soft cheeses Casseroles with small bits of tender meat, moist fish Soft, smooth chocolate and biscuits
Foods to avoid	Dry, crusty, seeded bread Non-moist sandwiches Crackers All raw vegetables, large, round, or dried fruit pieces Yoghurts with seeds, nuts etc Hard cheese Dry, tough, chewy meat Dry cakes, hard biscuits, crisps

Table 1: Texture A – Soft Diet

	Texture B- Minced and Moist
Description	Food is soft and moist and should easily form into a ball
Characteristics	Individual uses tongue rather than teeth to break up the small lumps Food is soft and moist and should easily form into a ball Food should be easily mashed with a fork Lumps are soft and rounded (no hard or sharp lumps)
Examples of recommended food	Breakfast cereals with small moist lumps Small, moist pieces of soft pasta, chopped noodles Tender cooked vegetables that are easily mashed with a fork Mashed soft fresh fruits Milk, milkshakes, smoothies, very soft cheese, yoghurt with soft fruit pieces Coarsely minced, tender meats/fish with a sauce Smooth puddings, dairy desserts, custards, yoghurt, and ice-cream Plain biscuits dunked in hot tea or coffee and completely saturated
Foods to avoid	All breads, sandwiches, pastries, crackers and dry biscuits Raw vegetables Fruit that cannot be mashed with a fork Sticky/chewy soft cheese Casseroles or mince dishes with hard or fibrous particles, eg: peas, onion Desserts with large, hard or fibrous fruit particles (e.g. sultanas), seeds or coconut Soups with large meat/vegetable parts Sweets

Table 2: Texture B – Minced and Moist Diet

	Texture C- Smooth Pureed
Description	Food is smooth and lump free
Characteristics	Smooth and lump free but may have a grainy quality. Moist and cohesive enough to hold its shape on a spoon. Food could be moulded, layered or piped.
Examples of recommended food	Smooth, lump-free breakfast cereals. Pureed vegetables, fruits, meats, and fish Milk, milkshakes, smoothies, smooth puddings, and yoghurt
Foods to avoid	Cereals with coarse lumps and fibrous particles Raw vegetables Pureed fruit with visible lumps Crisps, cakes, sweets Minced/partially pureed meats Sticky/cohesive food Solid/semi-solid cheese Soups with lumps

Table 3: Texture C – Smooth Pureed Diet

	Texture D – Liquidised
Description	Food is a smooth, pouring, uniform consistency.
Characteristics	Smooth and lump free. Food has been pureed/sieved to remove any particles. Food does not hold their shape, they merge when placed side by side and as result are served in a bowl.
Examples of recommended food	Smooth, lump-free cereal and soup Liquidised vegetables, meats, fish, and fruits Milk, milkshakes, smoothies
Foods to avoid	Cereals with coarse lumps Raw vegetables Food with visible lumps Crisps, cakes, sweets Minced/partially pureed meats Sticky/cohesive food Solid/semi-solid cheese

Table 4: Texture D – Liquidised Diet

- **Sometimes, individuals experiencing TMDs modify their own diet to softer options due to pain and/or fatigue on chewing, or "locking" of the jaw resulting in limited mouth opening.**
- **This may result in you avoiding certain foods (e.g.: bread, hard and crunchy cereals, or meat) and eating an increased amount of softer, moistened foods (e.g.: ice cream, pasta, or yoghurt). In severe cases, you may avoid eating entirely due to severe pain and/or movement restrictions.**
- **Without receiving professional guidance from a qualified dietitian about these dietary changes, you may not be consuming a nutritionally balanced diet and may become malnourished due to reduced calorific intake. This can have a negative knock-on effect on healing, energy levels, and psychological well-being.**
- **However, you may also experience weight gain due to frequent consumption of softer, pre-prepared meals which do not contain the optimal balances of nutrients. This can also have negative effects on your physical and psychological functioning.**
- **It is advised that when you are recommended a modified diet or if you are modifying your own diet without guidance that you seek advice from both speech and language therapy and dietetics. These professionals will assess both eating, drinking, swallowing, and nutritional needs.**

Mealtime modifications

- There are some commonly recommended strategies and equipment that help make eating, drinking, and swallowing easier . These include:
  - Adapted utensils: Small spoons and forks reduce how much food you put into your mouth, therefore reducing how much food you have to chew in each mouthful, while also limiting how wide your mouth has to open.
    - Using wide bore straws can help you eat pureed or liquidised foods (e.g.: minced stews, smoothies, soups) by reducing how wide your mouth opens and reducing the work that your facial and oral muscle have to do.
    - Squeezable bottles also reduce demands on your face and jaw muscles as your hand muscles squeeze the liquid into your mouth[37,38].
  - Eating little and often: Fatigue can cause you to chew slowly, lengthening your mealtimes, sometimes resulting in unfinished meals, with potential unintentional weight loss. Eating regular small meals instead of 3 large meals can help pace your eating and can reduce fatigue [37].
  - Liquid wash-downs: if chewing becomes difficult due to pain/fatigue/jaw locking, food may remain in your mouth after swallowing, and this may be difficult to remove. It may be helpful to wash down remaining food with small mouthfuls of liquid. Sweeping your tongue on front of your gums and into the side of your mouth can also help remove residue.
  - Talking while eating: Both talking and eating place strain on your TMJ, and many people find talking while eating very difficult. Reduce talking while eating to improve TMJ pain and fatigue.
  - Environmental modifications: If you are experiencing pain and/or are fatigued, processing sensory information can be difficult. Reducing harsh/glaring light and background noise (e.g.: the radio, TV) when you are eating can help to reduce TMJ stress and discomfort [37].

Oral splints

- Oral splints are also commonly known as occlusal splints, occlusal appliances, bite guards, bite splints, or mouth guards.

Picture 2: Oral Splint

- Oral splints reduce tooth grinding to relieve TMJ pain and tension [38].
- Wearing the splint for two hours before bedtime may help re-train yourself to not grind/clench your teeth overnight.
- Please seek further advice from your oral surgeon.

Botulinum toxin injections

- Botulinum toxin (Botox) may relieve symptoms in certain people with TMDs (primarily myofascial pain disorder).
- Botulinum toxin is often used for individuals with significant clenching/grinding of the teeth [39].
- These injections partially paralyse the injected muscles. This makes it more difficult to clench or grind your teeth [39].
- Botulinum toxin injections must be re-administered frequently as the effects wear off after a period of time.

Surgery

- TMD-related eating, drinking, and swallowing difficulties may also be treated with surgery. Only a small percentage (up to 5%) of people will require surgery to relieve symptoms [40-42].
- **Surgical management techniques include:**
  - Arthroscopy,
  - Arthrocentesis,
  - Eminectomy,
  - High condylar shave,
  - TMJ Implants.

Arthroscopy

- Arthroscopy is a minimally invasive surgery.
- It involves inserting a small, lighted camera/arthroscope into the jaw joint through a minor cut on front of the ear [42].
- The surgeon can assess and diagnose certain forms of TMD that involve joint changes.
- The surgeon can also :
  - Wash out of the joint with anti-inflammatory medicine,
  - Alter the TMJ structure (e.g.: reposition the articular disc, removal of scar tissue, reshaping bony components) [43-44].
- Arthroscopies are typically completed under general anaesthetic.
- Arthroscopies can help reduce inflammation and can improve joint mobility, thus improving your ability to eat, drink, and swallow.

Picture 3: TMJ after arthroscopy showing paper stiches over incision

Arthrocentesis

- TMJ arthrocentesis is a minimally invasive surgical procedure.
- It is typically performed on patients with painful and reduced mouth opening due to disc displacements [45].
- It involves inserting two small needles into the TMJ to "wash out" the joint.
- The surgeon can also inject steroids into the joint to reduce inflammation.
- This may be done under local anaesthetic, local anaesthetic with conscious sedation, or general anaesthetic.
- This procedure reduces inflammation and increases joint mobility to improve eating, drinking, and swallowing[46].

Picture 4: TMJ after arthrocentesis showing mild bruising 1 day post-operation

Eminectomy

- Eminectomy is recommended for people experiencing "closed lock" of the TMJ [47].
- A "closed lock" happens when the TMJ disc moves out of the joint during mouth opening, and does not subsequently move back into the correct position during closing. This causes a mechanical lock of the joint [48].
- Eminectomy involves removing and remodelling of part of the joint (the articular eminence).
- By removing this part of the joint, the obstacle to the disc is removed and the "lock" should be relieved[48]. Therefore, chewing, swallowing, drinking, speaking, laughing, and yawning, should improve.
- This surgery may be done under general anaesthetic or local anaesthetic with conscious sedation and may be done on a day-case over over-night hospital stay basis [49].

Picture 5: Eminectomy scar day 2 post-operation

Picture 6: Eminectomy scar day 7 post-operation

High condylar shave

- A high condylar shave may also be known as a "high condylectomy".
- A high condylar shave remodels the upper section of the mandible/lower jaw[50].
- A high condylar shave is performed if the TMJ is diseased and eroded.
- This TMJ damage may be due to osteoarthritis or rheumatoid arthritis.
- Removal of the condylar section aims to reduce TMJ pain and inflammation along with improving functioning [51].
- It is typically performed under general anaesthetic.

TMJ implants

- TMJ implants may be recommended in some cases due to extremely restricted movement and severe pain [52].
- Patients who require TMJ implants typically present with:
  - Severe TMJ trauma,
  - Tumours,
  - Congenital deformities,
  - TMJ ankylosis,
  - TMJ osteoarthritis.
  - TMJ rheumatoid arthritis.
- TMJ implants involve the removal and remodelling of sections of the TMJ/the entirety of the TMJ.
- The joint is then rebuilt using metal/plastic/natural materials.
- It is performed under general anaesthetic.

Useful resources

- Jawpain.ie, Orofacial Pain and Temporomandibular Disorders: Www.Jawpain.Ie.
- Mayo Clinic – TMJ Disorders: http://www.mayoclinic.org/diseases-conditions/tmj/home/ovc-20209398.
- Mount Sinai: TMJ Disorders: http://www.mountsinai.org/health-library/diseases-conditions/tmj-disorders.
- NHS Choices- Temporomandibular Disorder (TMD): http://www.nhs.uk/conditions/temporomandibular-joint-disorder/Pages/Introduction.aspx.
- NIDCR- TMJ Disorders: https://www.nidcr.nih.gov/oralhealth/Topics/TMJ/Documents/TMJDisorders_100113_508C.pdf .
- The TMJ Association, Ltd.: Www.TMJ.org.
- TMJ Hope: http://www.tmjhope.org/.
- WebMD: Temporomandibular Joint Disorders (TMD, TMJ): http://www.webmd.com/oral-health/guide/temporomandibular-disorders-tmd#1.

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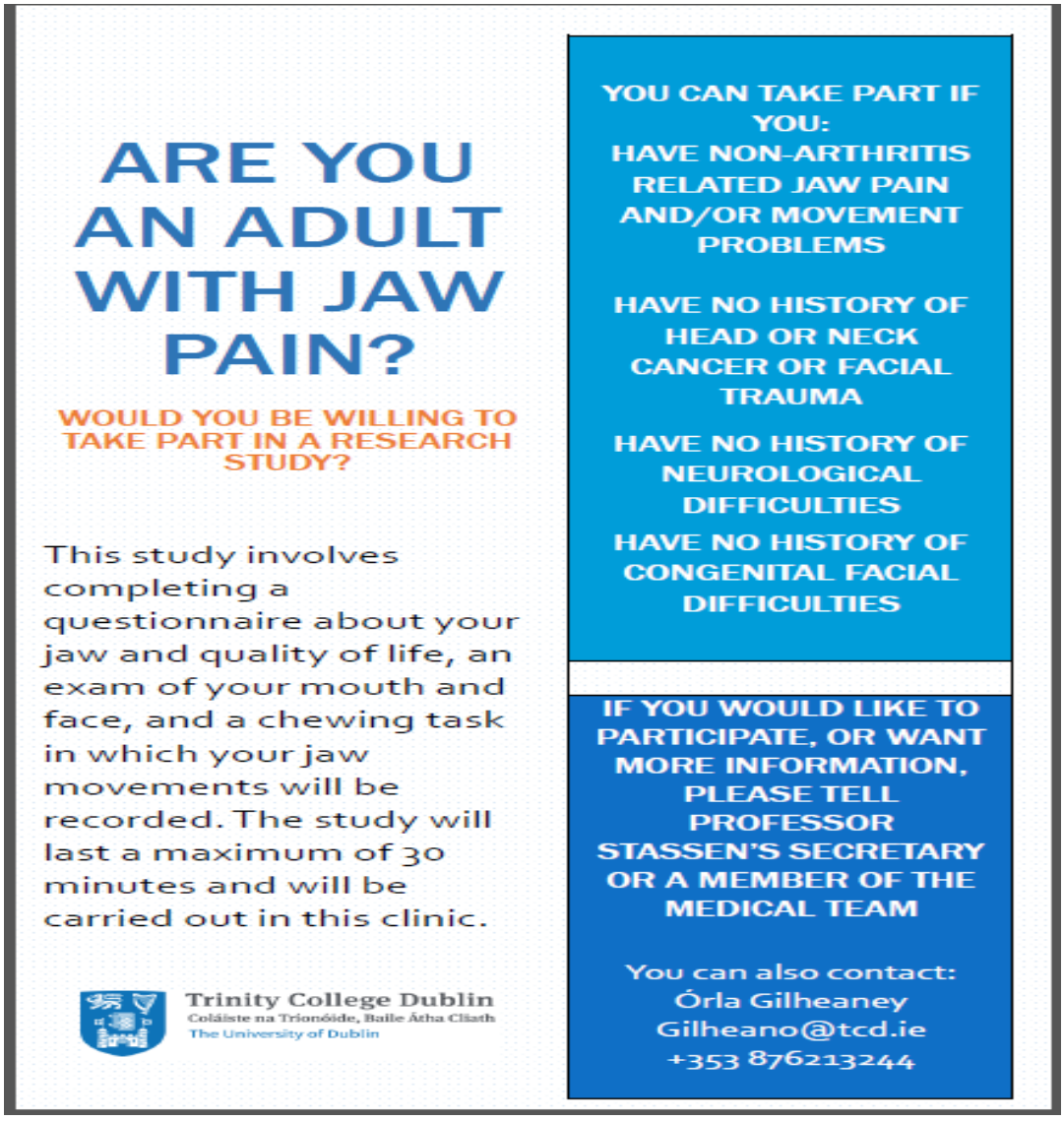
Appendix 28: Information Poster: The Prevalence, Nature, and Impact of Eating and Swallowing Problems in Adults with Temporomandibular Disorders



Appendix 29: Associated Publication: The Use of Modified Diets by adults with Temporomandibular Disorders: Systematic Review and Meta-analysis.

The use of modified diets by adults with temporomandibular disorders: systematic review and meta-analysis

Précis:

A systematic review of diet modifications in adults with TMDs was conducted, with 45% of these patients altering their diets to softer options.

Abstract:

Statement of the problem: Temporomandibular disorders (TMDs) are the most frequently reported non-dental orofacial pain disorders. Pain and dysfunction of the jaw joint and masticatory muscles may result in individuals modifying their diet to softer food options, which may not be nutritionally balanced and may have a subsequent negative impact on physical functioning and psychosocial well-being. However, little is known about the extent of diet modifications or their use as a compensatory strategy in this group. Therefore, clinical guidance to ensure continued adequate oral intake that does not exacerbate masticatory impairments, increase parafunctional behaviours, or compromise quality of life is not available, with potential impact on the individual's health, functioning, and psychosocial well-being.

Purpose of the study: The aim of this intervention review was to determine the prevalence of diet modification use in adults presenting with TMDs.

Materials and methods: A systematic review of available evidence was completed. Electronic databases searched from inception to January 2017, with no date/language restriction applied, were: Embase, PubMed, CINAHL, Web of Science, Elsevier Scopus, ScienceDirect, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. Additional searches of grey literature, conference proceedings, and reference lists were also conducted. Studies presenting original data regarding the prevalence of diet modifications among adults presenting with TMDs were included. Study eligibility and quality were assessed by two independent reviewers. Methodological quality was assessed using the Downs and Black assessment tool.

Results: This search yielded five eligible studies. Diet modification use was reported by 45% of adult patients with TMDs (confidence interval: 31.93-58.64). Eligible studies were rated, on average, to be of moderate quality. Study limitations included the few studies that met the inclusionary criteria.

Conclusions: Despite reported high levels of texture-modified diet use among adults with TMDs, little information exists on the typical methods of modification, the content of the diets consumed, or the impact of these diets on systemic health and psychosocial well-being. In addition, it is unclear if these patients typically have access to dietitians during TMD management. Therefore, further research is required in order to examine the true dietary intake of individuals with TMDs and to subsequently determine the most appropriate methods of supporting these individuals to maintain healthy and balanced levels of oral intake.

Key words: Dysphagia; swallowing disorders; deglutition; diet; diet modifications; temporomandibular joint; temporomandibular joint disorders.

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Table 1: Characteristics of included studies

Citation	Setting from which participants were recruited	Period of recruitment	Study design	No. of patients with TMDs studied	Female: male ratio	Mean age (SD) of patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (months)	Relevant outcome measured	Sources of assessment data	Study quality
Baker, *et al.*,[29] Sweden, 2015	University clinic	36 months	Randomised control trial (RCT)	34	10.3:1	38.9 (±15y)	Unclear	49.1 (unclear)	Diet modifications: 11.8%	RDC/TMD, X-ray, magnetic resonance imaging (MRI), IMPACT questionnaire, visual analogue scale, Jaw Functional Limitation Scale-8 (JFLS-8), Graded Chronic Pain Scale (GCPS), Symptom Checklist-90-Revised (SCL-90R)	15/18 Good
Foteder, *et al.*,[28] India, 2015	University hospital clinic	Six months	Cross-sectional	83	5.91:1	34.8 (±17.2)	Unclear	Unclear	Diet modifications: 53.1%	RDC/TMD, patient interviews, case history, Oral Health Impact Profile-14 (OHIP-14)	12/18 Moderate
Barros *et al.*[27] Brazil, 2008	University clinic	Four months	Cross-sectional	132	4.92:1	36.5 (±13.5)	Unclear	Unclear	Diet modifications: 50.6%	RDC/TMD, OHIP-14, clinical exam, temporomandibular index	13/16 Good
Brandini *et al.*,[26] Australia, 2011	Unspecified hospital	Unclear	Case-control	15	15:0	31.3 (±10.8)	Unclear	Unclear	Diet modifications: 60%	RDC/TMD, chewing task, numerical rating scale-II, Pain Self-efficacy Questionnaire, Fear-Pain Questionnaire-III, DAS-44, Pain Catastrophising Scale	13/18 Moderate
Reißmann *et al.*,[30] Germany, 2007	University clinic	66 months	Case-control	318	3.16:1	38.6 (±15.6)	Unclear	Unclear	Diet modifications: 55%	RDC/TMD, German version of OHIP, GCPS, Beschwerden-Liste, the Center for Epidemiologic Studies Depression Scale	10/18 Moderate

Introduction

Temporomandibular disorders (TMDs) affect the typical structure and/or function of the articular, osseous, and muscular elements of the temporomandibular joint (TMJ) complex.[1-3] TMDs occur frequently, with up to 93% of the general population reporting at least one symptom on examination (e.g., joint sounds or pain on palpation), and 20% of these individuals seeking treatment for symptom management.[4-12] TMDs cause pain and stiffness of the TMJ resulting in reduced ranges of mandibular motion and limited mouth opening.[13-15] As a result of these issues, most individuals with TMDs report oral preparatory masticatory impairments (e.g., reduced chewing effectiveness or efficiency).[16] In addition, the majority of these individuals also report that pain and fatigue further impair mastication (up to 100% and 99%, respectively).[17,18] Impaired chewing patterns may lead to individuals attempting to swallow large unmasticated solid boluses, potentially resulting in primary motoric difficulties (e.g., impaired oropharyngeal transit), secondary sensory experiences (e.g., "strangling" sensations), and tertiary emotional ramifications (e.g., anxiety about the potential for choking).[14] Research suggests that these issues may cause the individual to modify their typical oral intake to accommodate masticatory impairments and to avoid these adverse experiences.[14]

However, these texture-modified diets may not be nutritionally optimal and may be characterised primarily by pre-processed convenience food (e.g., lump-free soup, soft pasta, ready-made smoothies, ice cream, etc.). This may result in the consumption of an imbalanced diet lacking in recommended nutrients, vitamins, minerals, or food groups, and therefore, individuals with TMDs may be at risk of developing secondary systemic consequences (e.g., unintentional weight changes, heart disease, stroke, type 2 diabetes, and certain types of cancers).[19] In addition to systemic well-being, research within non-TMD groups has established that the consumption of a texture-modified diet is also associated with reduced health-related quality of life (HRQOL), due to limitations in food choices and reduced social participation.[20,21] Therefore, it is suggested that use of this compensatory strategy by patients with TMDs may also impact negatively on psychosocial well-being, activity, and participation. In light of these potential risks, individuals with TMDs may require clinical monitoring of their oral intake and body mass index, in conjunction with the provision of psychosocial supports, to ensure that their nutritional needs are adequately met and that impact on HRQOL is minimised.

However, limited research has been conducted to determine the extent and methods of diet modifications by individuals with TMDs. Therefore, appropriate population-specific clinical recommendations are not currently available, with potential impact on patient recovery, well-being, and experience of care. The aim of this research was therefore to systematically review all available evidence pertaining to the use of diet modifications by adults presenting with TMDs, with the view to informing the need for future research and development of evidence-based clinical interventions in this area.

Material and methods

This study was carried out in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement (PRISMA)[22] and the Guidelines for Meta-Analyses and Systematic Reviews of Observational Studies.[23]

Eligibility criteria

All available evidence (both published and unpublished), which provided data on the prevalence of modified diet use (e.g., avoidance of certain foods or consumption of a soft/puréed/minced moist diet to accommodate masticatory impairments) in adults presenting with TMDs, was eligible for inclusion. No

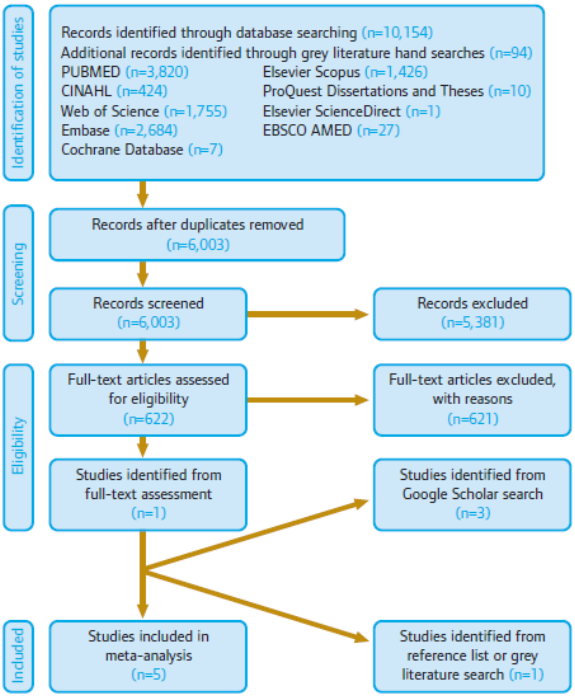

FIGURE 1: Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram.

restrictions relating to language, research location/setting, or date of publication were applied. Case studies were not eligible for inclusion due to critique regarding levels of evidence.

Data was sought regarding adult humans presenting with TMDs who reported consumption of modified diets as a compensatory strategy, with no eligibility restrictions applied (e.g., sex, race, disease duration, severity, age of onset, or recruitment location). Individuals were excluded if they reported a history of congenital, orthopaedic, traumatic, or cancerous conditions affecting the structure and/or function of the oral or maxillofacial area.

Data sources

A search strategy that accounted for filters, key-text, and medical subject headings, as appropriate, was systematically employed across nine electronic databases by two independent reviewers. The databases searched were: Embase, PubMed, CINAHL, Web of Science, Elsevier Scopus, ScienceDirect, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. Databases were searched from inception to January 2017, with all results exported using the Zotero reference management software (Zotero Software; George Mason University, USA). The titles and abstracts of all identified records were screened by two independent authors, with obviously ineligible studies excluded.

Hand searches of the proceedings of the annual scientific meetings of the European Society for Swallowing Disorders and the Dysphagia Research Society (both published in *Dysphagia*), and the International Association for Dental Research (published in the *Journal of Dental Research*) were conducted by the senior author, in conjunction with searches of the reference lists of eligible studies, available grey literature, and the Google Scholar database, in order to identify potentially eligible records not indexed in primary searches.

Data extraction process and data items

An electronic data extraction form, which has been previously piloted and described elsewhere,[13] was used by two independent reviewers, with a third author available to mediate disputes, if required. Full consensus regarding extracted data was reached by reviewers. In the case of missing/unclear data, the senior author contacted corresponding authors of primary studies published in the previous 10 years,[13] with exclusion of studies in the case of no response to two contact attempts.

Assessment of methodological quality

The methodological quality of included studies was rated by two independent reviewers using the Downs and Black assessment tool.[24] A third author was available to mediate disputes, if required.

Summary measures and synthesis of results

Descriptive analysis was initially conducted, with subsequent statistical analysis completed using the Microsoft Excel (Microsoft; Richmond, WY, USA) and the MedCalc Systems for Windows, version 15.0 (MedCalc Software; Ostend, Belgium)[25] to conduct both fixed and random effects meta-analyses of prevalence estimates. Prevalence figures were presented using 95% confidence intervals and displayed graphically using forest plots.

Results

Study identification

In total, searches of electronic databases resulted in 10,248 identified records (**Figure 1**). Subsequent to exclusion of duplicates and obviously ineligible results, 622 full-test studies were reviewed by two independent authors, resulting in the identification of one eligible study from these databases.[26] Additional Google Scholar searches resulted in identification of three further eligible articles,[27-29] with reference list searching identifying one subsequent study.[30]

Missing data or lack of article access within identified studies was addressed, as discussed, with three contact attempts relating to missing data and two relating to requesting access to articles. Therefore, five articles in total were eligible for inclusion in analysis.

Study characteristics

The characteristics of included studies are described in **Table 1**. The majority of eligible studies were cross-sectional (n=2;40%) or case-control studies (n=2;40%), with one study being classed as a randomised controlled trial (RCT) (n=1;20%). The location of eligible studies was broad, including northern Europe (n=2;40%), South America (n=1;20%), and Asia (n=1;20%). The settings of most included studies were university hospital clinics (n=4;80%). Outcome measurement tools included the Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD)[31] (n=5;100%) and subjective patient-reported questionnaires (n=5;100%). Only one study used assessments of masticatory performance to assess the individual's ability to tolerate varying levels of oral intake.[26]

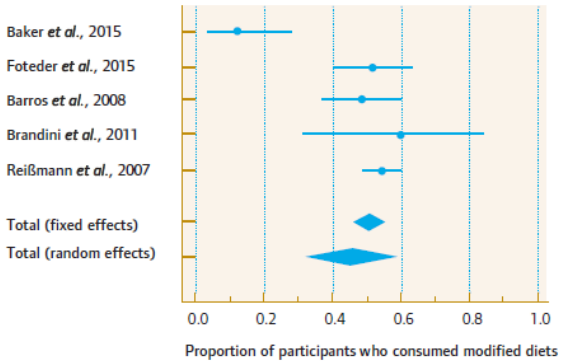

FIGURE 2: Forest plot of prevalence of diet modifications.

Description of participant demographics

Data pertaining to 533 patients were eligible for inclusion, with an overall mean age of 36 years of age (**Table 1**). No included study provided age ranges for participants. In total, 420 females and 113 males (3.71:1) were eligible for inclusion. Included studies varied as to whether they reported one primary diagnosis per overall participant or one diagnosis per unilateral TMJ. Myofascial pain was the most frequently reported diagnosis (n=266), while disc displacements were also commonly reported (disc displacement with reduction: n=156; disc displacement without reduction: n=55; disc displacement without reduction and arthralgia: n=34). Arthralgia was common, with 141 participants receiving this diagnosis, while a cohort was diagnosed with osteoarthritis (n=27) or osteoarthrosis (n=9).

Assessment of methodological quality of included studies

Reviewers reached full consensus regarding ratings of methodological quality. On average, studies were deemed to be of moderate quality (**Table 1**). The items that predominantly contributed to lower methodological quality ratings were: inadequate descriptions or measurement of confounding factors; and, inadequate blinding of assessors. A range of items contributed to positive ratings, including adequate description of null hypotheses/aims and the use of valid and reliable outcome measurement tools.

Prevalence of diet modifications

Based on data extracted from five studies (n=533),[26-30] the prevalence of diet modifications was estimated to be 45.1% (confidence interval: 31.93-58.64) (**Figure 2**).

Discussion

This study demonstrated that diet modifications are commonly used as a compensatory strategy by adults with TMDs who experience impaired mastication, although this topic has typically received limited research attention. Research on eating and swallowing problems in other clinical cohorts suggests that consuming a modified diet negatively impacts overall physical health. In addition, HRQOL is also often affected as food choices are restricted and participation in social events is reduced.[20,21] However, little is known about the impact of diet modifications in adults with TMDs on physical functioning and psychosocial well-being. It is hypothesised that if diets are modified, they may not be nutritionally balanced and may lack key nutrients or calories. Research has found that the modified diets consumed by people with eating and swallowing problems typically contain significantly lower levels of energy and protein than those consumed by healthy controls.[21] In addition, patients consuming modified diets also demonstrate significantly greater energy and protein deficits than healthy controls, potentially increasing the risk of unintentional weight loss.[21] Finally, modified diets often contain higher levels of sugar[32] and lower levels of fibre than recommended,[33] with the potential for the development of subsequent gastrointestinal difficulties, such as constipation.[34] In other clinical groups who experience eating and swallowing problems, the dietitian typically evaluates and manages these potential risks to weight and systemic health, as part of the wider multidisciplinary team (MDT).[35,36] However, it is unclear if patients with TMDs typically have access to dietitians during TMD management. Therefore, this study is significant as it indicates the need for increased research in this field to inform the development of both evidence-based management strategies and the expansion of typical MDT structures.

Study limitations

The primary limitations were the limited number of studies that satisfied the strict inclusion criteria, and the lack of population-based studies available for inclusion. Therefore, true prevalence rates may be different to estimates presented here. Also, only one study used masticatory assessments to determine the most appropriate levels of oral intake.[26] Therefore, the use of subjective questionnaires in the majority of included studies may underestimate levels of modified diet use, with ultimate impact on the accuracy of prevalence figures. As such, it is recommended that large-scale, population-based research using subjective and objective assessments is conducted to further our understanding of these issues.

Recommendations

It is advised that subsequent research should address a range of issues, including:

- examination of the true dietary intake of adults with TMDs to determine if they are consuming the recommended levels of nutrients, vitamins, and energy;[37]
- investigation of the potential systemic and psychological implications of consuming texture-modified diets over both short periods of symptom flare-ups and longer periods of chronic dysfunction within this cohort; and,
- investigation of the need to include professionals such as the dietitian in future TMD MDTs.

Conclusions

This systematic review and meta-analysis demonstrated that adults with TMDs commonly use diet modifications as a compensatory strategy to accommodate masticatory impairments. It is hypothesised that these individuals may not be consuming nutritionally balanced diets in accordance with international guidelines, thus introducing the potential for secondary health and social consequences. Therefore, further evidence-based research is required to examine the true dietary intake of individuals with TMDs, and to subsequently determine the most appropriate methods of supporting these individuals to

maintain healthy and balanced levels of oral intake, with the ultimate view to improve clinical care provision and patient well-being and recovery.

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CPD QUESTIONS

To claim CPD points, go to the MEMBERS' SECTION of www.dentist.ie and answer the following questions:

1. **Common signs and symptoms of TMDs include:**
   a. Reduced ranges of mandibular motion
   b. Limited mouth opening
   c. Impaired mastication
   d. All of the above

2. **Patients with TMDs may be at greater risks of unintentional weight changes due to the consumption of modified diets.**
   a. True
   b. False

3. **Almost half of all patients with TMDs consume modified diets due to masticatory issues:**
   a. True
   b. False

Appendix 30: Associated Publication: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders associated with Rheumatoid Arthritis: A Systematic Review and Meta-analysis

Dysphagia (2017) 32:587–600
DOI 10.1007/s00455-017-9808-0

REVIEW ARTICLE

The Prevalence of Oropharyngeal Dysphagia in Adults Presenting with Temporomandibular Disorders Associated with Rheumatoid Arthritis: A Systematic Review and Meta-analysis

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Abstract Temporomandibular disorders (TMDs) are the most frequent non-dental orofacial pain disorders and may be associated with rheumatoid arthritis (RA), resulting in oropharyngeal dysphagia (OD). However, clinicians' understanding of involvement with OD caused by RA-related TMDs is limited and the methodological quality of research in this field has been criticised. Therefore, the aim of this study was to systematically review the prevalence of oral preparatory and oral stage signs and symptoms of OD in adults presenting with TMDs associated with RA. A systematic review of the literature was completed. The following electronic databases were searched from inception to February 2016, with no date/language restriction: EMBASE, PubMed, CINAHL, Web of Science, Elsevier Scopus, Science Direct, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. Grey literature and reference lists of the included studies were also searched. Studies reporting the frequency of OD in adults presenting with TMD and RA were included. Study eligibility and quality were assessed by three independent reviewers. Methodological quality was assessed using the Down's and Black tool. The search yielded 19 eligible studies. Typical difficulties experienced by RA patients included impaired swallowing (24.63%), impaired masticatory ability (30.69%), masticatory pain (35.58%), and masticatory fatigue (21.26%). No eligible studies reported figures relating to the prevalence of weight loss. Eligible studies were deemed on average to be of moderate quality. Study limitations included the small number of studies which met the inclusion criteria and the limited amount of studies utilising objective assessments. Valid and reliable prospective research is urgently required to address the assessment and treatment of swallowing difficulties in RA as TMJ involvement may produce signs and symptoms of OD.

Keywords Dysphagia · Rheumatoid arthritis · Temporomandibular joint · Temporomandibular joint disorder · Prevalence · Deglutition · Deglutition disorders

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Introduction

Rheumatoid arthritis (RA) is a systemic autoimmune disorder of unknown aetiology affecting 1–3% of adults [1, 2]. It is characterised by progressive immune-mediated polyarticular inflammation of symmetrical synovial joint tissue, with frequent findings of joint effusion and synovial proliferation, progressing to joint destruction and/or ankylosis [3–8]. The average age of RA onset is between age 35 and 55 years, and this prevalence increases with age [1]. The female-to-male ratio is 2.5:1 [8]. Survival is 20% lower than healthy controls and increased mortality directly correlates with the severity of RA [9, 10]. The clinical course of RA is characterised by repeated remissions and exacerbations [6, 11]. Although RA typically affects small diarthrodial joints [11–13], peripheral manifestations of this pathology can include involvement of the temporomandibular joint (TMJ) which occurs in up to 84% of RA

patients [14–17]. Such involvement can potentially result in the development of concomitant temporomandibular disorders (TMDs) [11, 18, 19].

The most frequent orofacial pain disorders of non-dental origin are TMDs [20–24]. TMDs are a range of conditions commonly characterised by heterogeneous signs and symptoms and are reported to be the second most common musculoskeletal/neuromuscular disorders [20, 22, 25–28]. The prevalence of TMDs is controversial, with at least one sign or symptom estimated in up to 93% of the general population [29–32], with 10–20% of this cohort seeking treatment at some point [33–36]. TMDs are reported two to eight times more frequently in women than men. This is thought to be connected to oestrogen production, as exemplified by prevalence peaks in the second to fourth decades and decline during menopause [20, 30, 37–40]. TMDs are important to research, as symptoms have the potential to influence quality of life (QOL) [41, 42].

Typical findings in individuals presenting with TMDs associated with RA include joint sounds, myalgia of the associated musculature, and restricted mandibular movement [5, 10, 13, 43–45]. Bony TMJ destruction begins early in the RA disease process and can be objectively detected at 6 months post onset [43], with the most frequent radiographic findings at 5–10 years post onset including erosion, flattening, and resorption of the condyle [46–49]. Joint deformation can result in the development of signs and symptoms of oropharyngeal dysphagia (OD) [10, 13, 48, 50, 51]. For example, a range of oral preparatory and oral stage OD signs and symptoms relate to restricted ranges of mandibular motion, such as masticatory difficulties, masticatory pain and fatigue, increased oral transit times, and reduced cohesive bolus formation, with the potential for unintentional weight loss [52]. It is acknowledged that these signs and symptoms of OD can reduce oral health-related QOL and wellbeing within the RA population [53–55].

While research advocates the early management of RA-related TMDs via a myriad of methods which include ongoing objective and/or subjective assessments, pharmaceutical interventions, and diet modifications among other techniques [56], the medical profession's acknowledgment of the presence and impact of RA-related oral manifestations would seem limited [10, 57], with physicians often prioritising the treatment of upper extremity and weight-bearing joints [13]. This may be in response to methodologically limited studies which under-emphasise the prevalence and impact of OD, perpetuating such practice patterns. In light of these clinical and research limitations, further research investigating the prevalence, nature, and potential impact of OD caused by RA-related TMDs is warranted.

The purpose of this study was to systematically review the epidemiology of oral stage signs and symptoms of OD within adults presenting with RA-related TMDs. Research aims were to examine the prevalence of the following oral stage OD signs and symptoms within the cohort of interest: impaired swallowing and masticatory ability, masticatory pain and fatigue, and unintentional weight loss.

Materials and Methods

This systematic review was executed in line with The PRISMA statement [58] and MOOSE guidelines [59]. The protocol was prospectively published on the University of York Centre for Reviews and Dissemination Prospero database (Registration number: CRD42016033528) [60]. For the purpose of this review, OD was defined as sensory and/or motor difficulties in the movement of a liquid or solid bolus from the oral cavity to the oesophagus, inclusive of concomitant emotional, cognitive, and functional difficulties [61].

Eligibility Criteria

All published/unpublished studies providing original prevalence figures were eligible for inclusion, with no language, geographic, or date limitations. Case reports were not included due to their low levels of evidence. Data regarding humans aged 18 years and over of any gender or race seen in any setting presenting with signs/symptoms of OD caused by RA of the TMJ were sought, with no disease duration, severity, or age-of-onset limitations. Individuals were excluded if they presented with a history of relevant comorbid conditions affecting the mandibular area (e.g., cancer of the head and/or neck, facial trauma, neurological injuries to the facial region). Individuals with histories of comorbid/congenital conditions affecting the mandibular or head and neck region were also excluded.

Outcomes of Interest

Outcomes investigated in this review included the following:

1. impaired swallowing and mastication as reported subjectively and/or detected objectively through clinical examination, interviews, questionnaires, and/or imaging techniques;
2. masticatory pain as reported via interviews, questionnaires, or as rated using subjective scales;
3. masticatory fatigue as reported via interviews and questionnaires, or detected via clinical or electromyographic assessment; and

4. unintentional weight loss as reported by the patient or detected via clinical examinations.

Data Sources

A sensitive search strategy using filters, MeSH, and key-text terms was systematically employed ("Appendix 1" section). Databases searched from inception to February 2016 were EMBASE, PubMed, CINAHL, Web of Science, Elsevier Scopus, Science Direct, AMED, The Cochrane Database of Systematic Reviews, and ProQuest Dissertations and Theses A & I. All records were exported to the Zotero bibliographic system (www.zotero.org). Following duplicate deletion, screening of titles/abstracts was independently conducted by three authors to exclude obviously irrelevant papers. Two of these authors screened one-third of potentially relevant records, two screened another third, and two others screened the final third. A fourth reviewer mediated disputes if they occurred. Hand-searches of the annual conference proceedings of the American College of Rheumatology (published in *Arthritis and Rheumatology*) and the International Association for Dental Research (published in the *Journal of Dental Research*), in conjunction with reference list searches of eligible studies, were conducted, with no eligible results identified. Following completion of the systematic searches discussed above, the authors also searched the Google Scholar database to further identify any papers not indexed in the directories initially searched, resulting in one additional eligible study [62]. Eligible articles included in the review were subsequently analysed.

Data Extraction Process and Data Items

Following piloting of an electronic data extraction form on a random sample of 20% of eligible studies, three authors extracted data regarding study design and location, demographics, outcome measurement, prevalence, and statistical analysis, among other parameters, reaching 100% agreement. One author not involved in data extraction mediated disputes. Two authors addressed missing data by contacting authors of studies published within the last 10 years. The period of 10 years was selected to allow for both the typical 5-year retention period observed in research and to also avoid forcible exclusion of studies if they were dated beyond this period, yet records were retained for post hoc analysis subsequent to expiration of the retention period. Exclusion of records occurred following no response to two contact attempts. Author contact was also carried out if prevalence figures were not directly reported in the primary study or if the authors were unable to calculate prevalence from the provided data.

Assessment of Methodological Quality

Methodological quality was independently examined by two authors using a modified version of the Down's and Black tool [63] (Table 3 in "Appendix 2" section). This was modified to omit criteria regarding intervention, adverse events, blinding, and randomisation as these parameters were not relevant to this study's aims. The authors reached 100% agreement regarding ratings. Primary studies which included a comparison group were marked out of a total of 18 points, while those without comparison groups were only scored out of a total of 16 points, as two criteria directly referred to the presence of a control group. Methodological quality was further independently rated by two authors using an adapted tool which was a combination of the Joanna Briggs Institute (JBI) [64] and Boyle critical appraisal checklists [65] (Table 4 in "Appendix 3" section). This adapted tool was used as a supplementary measure of methodological quality in order to pilot its use as an assessment of risk of bias tool.

Summary Measures and Synthesis of Results

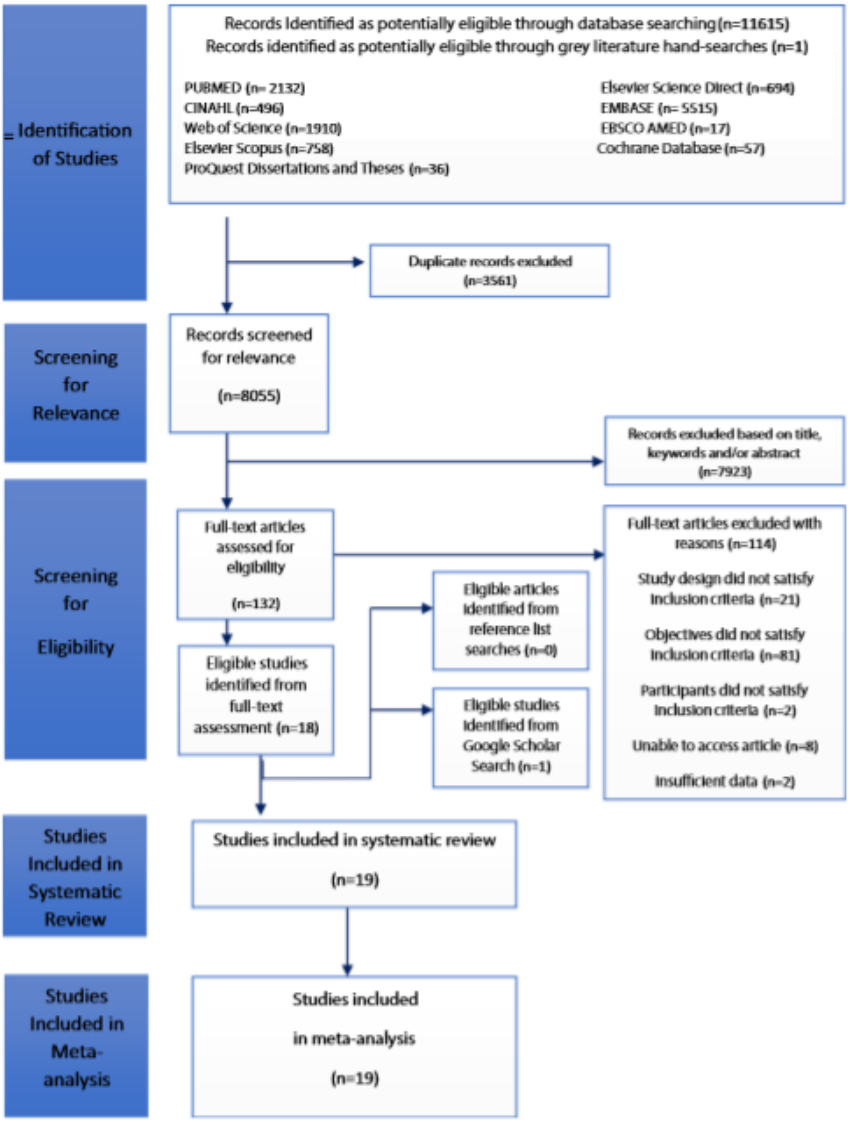
The main characteristics of included studies were first described descriptively. Data from eligible studies were statistically analysed. Random-effects meta-analyses of prevalence estimates were conducted using the R statistical package (R core team, 2013, Austria). Prevalence was reported with 95% confidence intervals, with forest plots constructed for all prevalence estimates.

Results

Study Identification

Systematic searches yielded 11,616 results, as shown in the PRISMA figure below (Fig. 1). Duplicate deletion resulted in the exclusion of 3561 records. The authors examined 132 full-texts and made 43 contact attempts to 30 researchers regarding 20 studies. For 2 of these studies, missing data were sought, while 18 communications were related to article access. Contact led to 6 eligible studies, the exclusion of 7 irrelevant studies, and 2 studies excluded due to insufficient data. Five studies were excluded due to inability to contact authors. Review authors identified no additional eligible articles from reference list or grey literature searches. Supplementary Google Scholar searches identified 1 further eligible study [62]. Therefore, 19 studies were ultimately included in the analysis.

Fig. 1 PRISMA diagram



Characteristics of Included Studies

Characteristics of included studies are described in Table 1.

The majority of included records ($n = 13$) were case–control studies (68.42%), 21.05% ($n = 4$) were descriptive observational studies, and 10.52% ($n = 2$) were cross-sectional studies. Study locations included South America ($n = 3$; 15.78%), Central America ($n = 1$; 5.26%), Europe ($n = 11$; 57.89%), Africa ($n = 1$; 5.26%), and the Middle East ($n = 1$; 5.26%). University hospital rheumatology clinics were the setting of the majority of studies ($n = 10$; 52.63%) (Table 1). Data pertaining to 1400 patients presenting with RA were extracted across 19 studies. The pooled age range of RA patients was 18–82 years, although 36.8% ($n = 7$) of studies did not provide details of age.

A majority of 84.21% of studies ($n = 16$) employed clinical stomatognathic evaluations and/or case histories and interviews ($n = 7$; 36.84%) as assessment tools. Questionnaires investigating symptoms, QOL, or participation were utilised in 52.63% ($n = 10$) of studies. Objective assessments, such as X-rays ($n = 7$; 36.84%), computed tomography ($n = 3$; 15.78%), laryngoscopy ($n = 1$; 5.26%), and MRI ($n = 1$; 5.26%), were utilised in several studies.

Table 1 Characteristics of included studies

Citation	Year of publication	Region from which participants were recruited	Setting from which participants were recruited	Year of recruitment	Study design	No. of RA patients	Female:male ratio
Franks [68]	1969	England	Rheumatology Hospital	NA	Case–control	100	3:1
Chalmers and Blair [73]	1973	Not-stated	NA	NA	Case–control	100	3:1
Ogus [74]	1975	England	General Hospital	NA	Case–control	62	2.8:1
Larheim et al. [69]	1983	Sweden	Health centre	NA	Case–control	49	4:1
Ekberg et al. [66]	1987	Sweden	Radiology and Internal Medicine Department, University Hospital	NA	Descriptive observational	31	4.1:1
Tegelberg [80]	1987	Sweden	Rheumatology Hospital	1982–1983	Case–control	151	4:1
Könönen et al. [75]	1992	Sweden	Rheumatology Department, University Hospital	NA	Case–control	61	7:1
Goupille et al. [76]	1993	Not-stated	Not-stated	NA	Case–control	26	5.5:1
El-Assy et al. [62]	1994	Egypt	Rheumatology Department, University Hospital	NA	Case–control	30	9:1
Kallenberg et al. [67]	1997	Sweden	Rheumatology Department, University Hospital	NA	Case–control	81	10.5:1
Voog et al. [77]	2003	Estonia	Stomatology Clinic, University Hospital	NA	Descriptive observational	19	8.5:1
Helenius et al. [78]	2005	Finland	Rheumatology Department, University Hospital	September 1996 – August 1998	Case–control	24	11:1
Bessa-Nogueira et al. [10]	2008	Brazil	Rheumatology Department, University Hospital	December 2003 – December 2004	Descriptive observational	61	9:1
Yilmaz et al. [70]	2012	Turkey	Rheumatology Department, University Hospital	NA	Case–control	28	13:1
Aceves-Avila et al. [71]	2013	Mexico	Rheumatology Department, University Hospital	September 2010–February 2011	Case–control	92	NA
Ahmed et al. [79]	2013	Saudi Arabia	Rheumatology Department, University Hospital	NA	Descriptive observational	33	7.25:1
Bono et al. [72]	2014	Argentina	Rheumatology Department, University Hospital	NA	Case–control	95	5:1
Ahola et al. [53]	2015	Finland	Database of Finnish Rheumatism Association	NA	Cross-sectional	282	NA
Hoyuela et al. [54]	2015	Brazil	Rheumatology Department, University Hospital	July 2020 – February 2012	Cross-sectional	75	NA

Table 1 continued

Citation	Mean age (range) of RA patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (years)	Main outcome	Sources of assessment data	Study quality score: Down's and Black checklist
Franks [68]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Impaired mastication present in 69% of participants	Subjective questionnaire, clinical exam, X-ray and CT imaging	12/16
Chalmers and Blair [73]	NA (18–77)	42 (16–73)	11 (0.2–47.0)	Masticatory pain present in 10% of participants	Clinical exam and CT imaging	11/18
Ogus [74]	NA (21–79)	NA (NA–NA)	NA (NA–NA)	Masticatory pain present in 36% of participants	Clinical exam, patient interviews, and CT imaging	11/18
Lazheim et al. [69]	58 (NA–NA)	36 (17–75)	22 (1–49)	Impaired mastication present in 2.04% of participants	Clinical exam, patient interviews, and X-ray imaging	8/18
Ekberg et al. [66]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Impaired swallowing present in 33.3% of participants	Cineradiography	7/16
Tegelberg [80]	NA (21–82)	NA (NA–NA)	NA (NA–NA)	Masticatory fatigue present in 55% of participants	Dental and medical history, clinical dysfunction score, Eichner Index, Helkimo Anamnestic Index, Ritchie Index, Lee Index, erythrocyte sedimentation rate, C-reactive protein, Skin surface temperature measurements	14/18
Könönen et al. [75]	NA (24–80)	NA (NA–NA)	NA (NA–NA)	Masticatory pain present in 25% of participants	Subjective questionnaire, clinical exam, and Helkimo Anamnestic Index	8/18
Goupille et al. [76]	62.1 (50.3–73.9)	53.3 (39.3–67.3)	8.7 (5–51)	Masticatory pain present in 19.23% of participants	Clinical exam, patient interviews, and CT imaging	11/18
El-Assy et al. [62]	NA (30–60)	NA (NA–NA)	NA (1–20)	Masticatory pain present in 50% of participants	Case history; clinical TMJ exam; ENT exam; direct and indirect laryngoscopy, audiological evaluation, laboratory blood testing; radiological assessment	16/18
Kallenberg et al. [67]	56.1 (22–80)	NA (NA–NA)	NA (NA–NA)	Masticatory fatigue present in 20% of participants; Impaired swallowing present in 31% of participants; Impaired mastication present in 19% of participants	Subjective questionnaires, Helkimo Anamnestic Index, Body Symptom Scale, Mood Adjective Checklist	15/18
Voog et al. [77]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Masticatory pain present in 95% of participants	ADL scale, rheumatoid factor, erythrocyte sedimentation rate, C-reactive protein; visual analog scale, clinical exam, electronic pressure algometer	11/16
Helenius et al. [78]	48.9 (37.5–60.3)	NA (NA–NA)	10.5 (7.9–13.1)	Masticatory pain present in 42% of participants	Subjective questionnaire, clinical and stomatognathic exam, X-ray	16/18

Table 1 continued

Citation	Mean age (range) of RA patients (years)	Mean age (range) of onset (years)	Mean disease duration (range) (years)	Main outcome	Sources of assessment data	Study quality score: Down's and Black checklist
Bessa-Nogueira et al. [10]	NA (24–76)	NA (NA–NA)	NA (NA–NA)	Impaired mastication present in 39.3% of participants; Impaired swallow present in 13.10% of participants	Clinical exam, patient interviews, Health Assessment Questionnaire, visual analog scales	11/16
Yilmaz et al. [70]	NA (35.51–52.49)	NA (NA–NA)	NA (NA–NA)	Impaired mastication present in 37.9% of participants	Clinical examination, erythrocyte sedimentation rate, C-reactive protein, rheumatoid factor, DAS-28, X-ray, MRI	12/16
Aceves-Avila et al. [71]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Impaired mastication present in 26% of participants	Subjective questionnaire, clinical exam, and case history	15/18
Ahmed et al. [79]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Masticatory pain present in 74% of participants	Clinical exam, DAS-28. Blood sampling, visual analog scale	13/16
Bono et al. [72]	45 (24–74)	NA (NA–NA)	10.5 (2–39)	Impaired mastication present in 23.24% of participants	Clinical exam, DAS-28, Health Assessment Questionnaire, X-ray	10/18
Abola et al. [53]	NA (NA–NA)	NA (NA–NA)	NA (NA–NA)	Impaired mastication present in 54.25% of participants; Masticatory pain present in 12.41% of participants; Masticatory fatigue present in 6.02% of participants	Subjective questionnaire, Oral Health Impairment Profile	16/18
Hoyuela et al. [54]	NA (NA–NA)	NA (NA–NA)	12.66 (NA–NA)	Impaired mastication present in 17.3% of participants	Clinical exam, dynamometer, OHIP-14, DAS-28, dynamometer, Health Assessment Questionnaire, Disabilities of the Arm, Shoulder and Hand questionnaire	15/18

Assessment of Methodological Quality of Included Studies

Two authors independently reached consensus regarding quality ratings, without disagreements. Utilising the Down's and Black tool, studies were awarded an average score of 11.5, indicating a typical standard of moderate quality (Table 2).

Ratings awarded utilising the modified Down's and Black tool and amended JBI-Boyle checklist were highly correlated, with both tools providing overall average ratings of moderate quality.

The main items responsible for lower ratings of methodological quality were as follows: lack of estimates of random variability regarding main outcomes provided within 14 primary studies (73.68%); lack of description of the distribution of principal confounders in 7 studies (36.84%); and the lack of adequate accounting for confounding factors within statistical analysis in 7 studies (36.84%). Similarly, the lack of sufficient details provided in 11 primary studies (57.89%) to determine if samples were representative of the target population impacted negatively upon overall quality ratings. Contributing to positive quality ratings was the judgement that all studies ($n = 19$) described primary aims, hypotheses, and outcomes clearly, alongside all studies employing appropriate statistical tests within their analyses.

Table 2 Down's and Black checklist rating criteria

Descriptor	Criteria for studies with comparison group	Criteria for studies with no comparison group
Poor quality	0–4	0–3
Fair quality	5–9	4–7
Moderate quality	10–14	8–11
Good quality	15–18	12–16

Prevalence of Investigated Outcomes

Based on estimates from three studies ($n = 173$ patients) [10, 66, 67], the prevalence of impaired deglutition was 24.63% (95% CI 14.21–39.2%) (Fig. 2).

An impaired ability to chew food was reported in nine studies ($n = 863$ patients) [10, 53, 54, 67–72]. The prevalence was calculated to be 30.69% (95% CI 19.24–45.14%) (Fig. 3).

Masticatory pain was reported in nine studies ($n = 637$ patients) [53, 61, 73–79], with the prevalence of this calculated to be 35.58% (95% CI 20.56–54.10%) (Fig. 4).

Masticatory fatigue was reported in three studies ($n = 514$ patients) [67, 79, 80]. This prevalence was calculated to be 21.26% (95% CI 4.10–63.01%) (Fig. 5).

Although specified as an outcome of interest, the prevalence of weight loss was not investigated in any included study.

Discussion

The findings of this systematic review and meta-analysis are noteworthy as they highlight the spectrum of OD signs and symptoms associated with RA-related TMDs, along with the limited research attention historically afforded to this condition. Impaired deglutition was present in 25% of RA patients, yet the included studies were characterised by methodological limitations restricting the validity and reliability of results. Therefore, the true prevalence may be higher than estimated in this study. Notably, 2 of the 3 included studies which addressed swallowing [10, 67] used only subjective questionnaires, while only 1 used objective imaging [66]. The frequent reliance on subjective assessments underlines the need for the increased use of combined subjective and objective assessments within TMD studies to ensure the validity and reliability of findings.

The disease processes involved in RA can cause occlusal changes and restricted TMJ movement, both of which can impair mastication [81]. Impaired mastication was estimated in approximately 31% of RA patients.

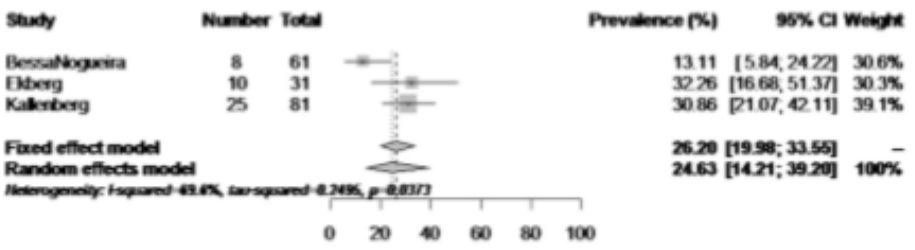


Fig. 2 Forest plot of the prevalence of impaired swallowing

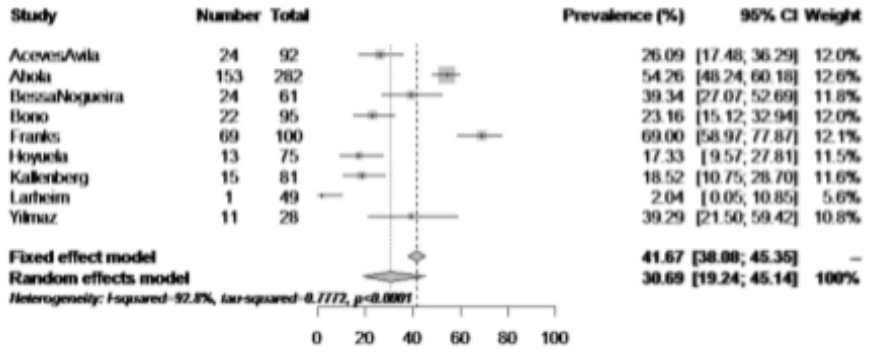


Fig. 3 Forest plot of the prevalence of impaired mastication

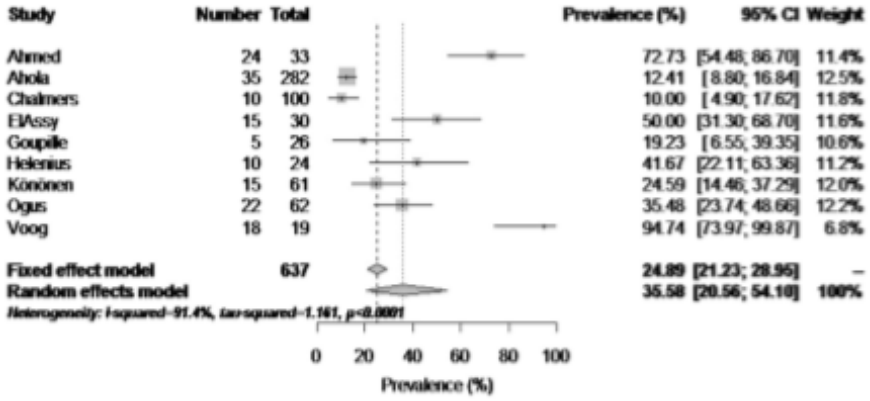


Fig. 4 Forest plot of the prevalence of masticatory pain

However, methodological limitations render it difficult to determine true prevalence rates. For example, Larheim et al. [69]. described impaired chewing in 1 patient, yet no information is available regarding whether more patients were affected. Yilmaz et al. [70]. also reported chewing difficulties in 37.9% of RA patients, but it is unclear if difficulties were present in controls, and there were no responses to attempts to access supplementary data. As such, the provision of full datasets may be beneficial in future investigations of the epidemiology of masticatory difficulties.

This study estimated that a third of RA patients experienced masticatory pain (36%). This figure is higher than estimates from individuals experiencing TMDs of other etiologies. Chalmers and Blair [73] estimated that 10% of RA patients experienced masticatory pain, compared to 2.1% of mixed osteoarthritis/healthy controls, while Ogus [74] found masticatory pain in 19.23% of RA patients and 3.85% of controls. Similarly, Helenius et al. [78]. reported masticatory pain in 42% of RA patients, yet only 21% of controls. Masticatory pain may be related to RA inflammatory joint destruction, internal derangement, capsule stretching, synovitis, and muscle tenderness. As inflammatory joint changes are central to RA pathology, the epidemiology of this pain is crucial to investigate if patients are to be managed effectively.

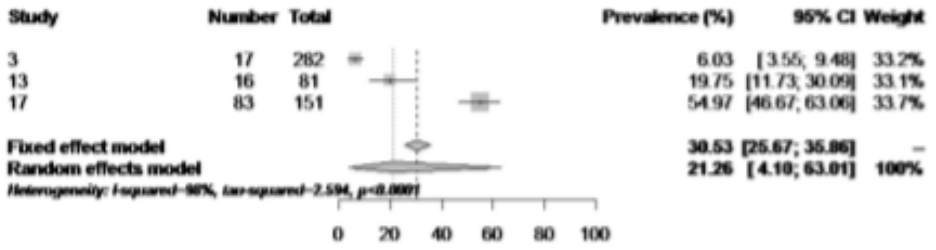


Fig. 5 Forest plot of the prevalence of masticatory fatigue

Global and chronic fatigue originates from the pain, sleep difficulties, and emotional disturbances which often accompany RA [82]. The prevalence of specific masticatory fatigue was calculated to be 21%. Masticatory fatigue in individuals with RA is crucial to investigate further as it has been shown within wider OD clinical cohorts to result in lengthened mealtimes, reluctance to eat in public, and reduced QOL [83].

Finally, weight loss is a frequent consequence of OD in non-RA populations, potentially resulting in malnutrition, increased risk of infection and depression, and reduced wound healing [84]. Weight loss can also increase OD severity by reducing muscle and nerve function [84]. While anecdotal evidence of TMD-related weight loss exists, no studies addressing this outcome were identified. Therefore, investigation of this parameter is warranted. Also, the clinical involvement of dieticians and speech language pathologists in multidisciplinary management may be beneficial for individuals with RA.

Limitations

One key limitation is that few available studies met the review's strict inclusion criteria. For example, case reports were excluded due to low levels of evidence and high propensity for bias [85]. This led to the exclusion of several records, which may have influenced estimates, despite methodological limitations. Also, only a limited number of eligible studies used objective assessments, with the subjective assessments used having varied psychometric properties. Finally, the conclusions presented are based on a small number of heterogeneous eligible studies. As such, reported frequencies are only estimates and true prevalence figures may be higher. Therefore, prospective epidemiological investigation of these parameters is warranted.

Recommendations

The use of inappropriate study designs in TMD research has been recently highlighted, with negative effects on methodological quality [10, 86]. The cross-sectional design is most appropriate for epidemiological investigations [87]. However, only two included studies used this design. Therefore, future TMD prevalence studies should adopt the cross-sectional design to increase methodological rigour. Recently, the American College of Rheumatology advised that low disease activity/remission with manageable pain levels and satisfactory levels of activity and/or QOL should be an RA treatment priority [88]. However, despite RA patients often experiencing OD, no evidence-based guidelines exist for its management. Therefore, remission/low disease activity levels may be unattainable, with residual TMJ complaints. Accordingly, rigorous research regarding OD caused by RA-related TMDs is required to ensure that patients are managed according to international best practice recommendations. Findings of this study should also motivate the development and validation of a psychometrically robust OD assessment for the RA and TMD populations, in order to inform management plans and improve the standard of care received by such patients.

Conclusions

This systematic review and meta-analysis indicate that OD is consistently reported by a small cohort of adults presenting with RA of the TMJ, and that a small amount of methodologically limited research has been conducted on this phenomena. This study emphasises the need for further psychometrically sound epidemiological research

regarding the presence, nature, and impact of OD in individuals with RA [89].

Compliance with Ethical Standards

Conflict of interest The authors have no conflict of interest to declare.

Appendix 1: Example of Database Search Strategy for PubMed

("Arthritis, Rheumatoid"[Mesh] OR Rheumatoid[Title/Abstract] OR Rheumatism[Title/Abstract] OR Rheumatology[Title/Abstract] OR Arthritis[Title/Abstract] OR Arthritic[Title/Abstract]) AND ("Deglutition"[Mesh] OR "Deglutition Disorders"[Mesh] OR "Temporomandibular Joint"[Mesh] OR "Temporomandibular Joint Disorders"[Mesh] OR "Stomatognathic System Abnormalities"[Mesh] OR "Skull"[Mesh] OR "Jaw"[Mesh] OR "Mastication"[Mesh] OR Dysphagia[Title/Abstract] OR Dysphagic[Title/Abstract] OR Deglutition[Title/Abstract] OR Swallow[Title/Abstract] OR Swallows[Title/Abstract] OR Swallowing[Title/Abstract] OR Swallowed[Title/Abstract] OR "Mouth Opening"[Title/Abstract] OR Mandibular[Title/Abstract] OR Mandible[Title/Abstract] OR Temporomandibular[Title/Abstract] OR Stomatognathic[Title/Abstract] OR Masticatory[Title/Abstract] OR Mastication[Title/Abstract] OR Jaw[Title/Abstract] OR Jaws[Title/Abstract] OR Skull[Title/Abstract] OR Skulls[Title/Abstract] OR Cranium[Title/Abstract] OR Calvaria[Title/Abstract] OR Calvarium[Title/Abstract]).

Appendix 2

See Table 3.

Table 3 Down's and Black checklist

	Yes (1 point)	No (0 points)	Unclear (0 points)
Hypothesis/aim/objective explicit			
Main outcomes clearly described in the introduction or methods section			
Characteristics of patients included clearly described			
Distributions of principal confounders in each group of subjects to be compared clearly described*			
Main findings clearly described			
Study provides estimates of random variability for main outcomes			
Characteristics of patients lost to follow-up described			
Actual probability values been reported for main outcomes except where probability value is less than 0.001			
Subjects representative of entire population			
Subjects prepared to participate representative of entire population			
Staff, places, and facilities representative			
Any of the results of the study were based on "data dredging"			
Appropriate statistical tests used to assess main outcomes			
Main outcome measures used accurate (valid and reliable)			
Adequate adjustment for confounding in the analyses			
Patients in different groups or cases and controls recruited from same population			
Subjects in different groups or cases and controls recruited over same time			

* Yes = 2 points; partially = 1 point; no = 0 points

Appendix 3

See Table 4.

Table 4 Amended JBI-Boyle checklist

	Yes (1 point)	No (0 points)	Unclear (0 points)
Representative sample			
Appropriate recruitment			
Adequate sample size			
Subjects and setting described in detail			
Data analysis conducted with sufficient coverage of identified sample			
Objective, standard criteria used for condition measurement			
Condition measured reliably			
Appropriate statistical analysis			
Inclusion of confidence intervals for statistical estimates			
Confounding factors/subgroup differences accounted for			
Subpopulations identified using objective criteria			

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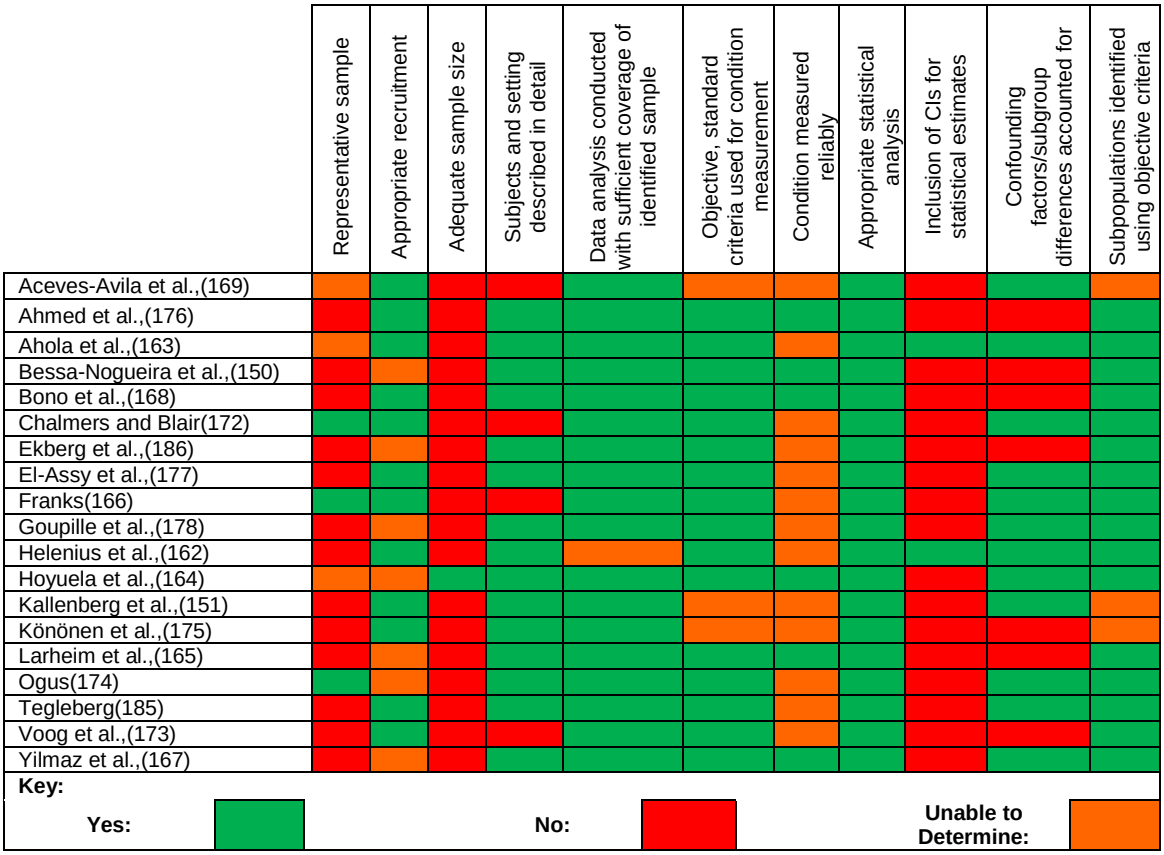
Appendix 31: Search Strategy: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders associated with Rheumatoid Arthritis: A Systematic Review and Meta-analysis

("Arthritis, Rheumatoid"[Mesh] OR Rheumatoid[Title/Abstract] OR Rheumatism[Title/Abstract] OR Rheumatology[Title/Abstract] OR Arthritis[Title/Abstract] OR Arthritic[Title/Abstract]) AND ("Deglutition"[Mesh] OR "Deglutition Disorders"[Mesh] OR "Temporomandibular Joint"[Mesh] OR "Temporomandibular Joint Disorders"[Mesh] OR "Stomatognathic System Abnormalities"[Mesh] OR "Skull"[Mesh] OR "Jaw"[Mesh] OR "Mastication"[Mesh] OR Dysphagia[Title/Abstract] OR Dysphagic[Title/Abstract] OR Deglutition[Title/Abstract] OR Swallow[Title/Abstract] OR Swallows[Title/Abstract] OR Swallowing[Title/Abstract] OR Swallowed[Title/Abstract] OR "Mouth Opening"[Title/Abstract] OR Mandibular[Title/Abstract] OR Mandible[Title/Abstract] OR Temporomandibular[Title/Abstract] OR Stomatognathic[Title/Abstract] OR Masticatory[Title/Abstract] OR Mastication[Title/Abstract] OR Jaw[Title/Abstract] OR Jaws[Title/Abstract] OR Skull[Title/Abstract] OR Skulls[Title/Abstract] OR Cranium[Title/Abstract] OR Calvaria[Title/Abstract] OR Calvarium[Title/Abstract]).

Appendix 32: Boyle-JBI Data: The Prevalence of Eating and Swallowing Problems in Adults presenting with Temporomandibular Disorders associated with Rheumatoid Arthritis: A Systematic Review and Meta-analysis

Boyle-JBI Methodological Quality Risk of Bias Table



Boyle-JBI Tool Scoring of Included Studies

Study Name	Score Awarded	Rating Awarded
Aceves-Avila et al.,(169)	4/11	Fair
Ahmed et al.,(176)	7/11	Moderate
Ahola et al.,(163)	8/11	Moderate
Bessa-Nogueira et al.,(150)	6/11	Moderate
Bono et al.,(168)	7/11	Moderate
Chalmers and Blair(172)	7/11	Moderate
Ekberg et al.,(186)	5/11	Fair
El-Assy et al.,(177)	7/11	Moderate
Franks(166)	7/11	Moderate
Goupille et al.,(178)	6/11	Moderate
Helenius et al.,(162)	7/11	Moderate
Hoyuela et al.,(164)	8/11	Moderate
Kallenberg et al.,(151)	5/11	Fair
Könönen et al.,(175)	4/11	Fair
Larheim et al.,(165)	6/11	Moderate
Ogus(174)	7/11	Moderate
Tegleberg(185)	7/11	Moderate
Voog et al.,(173)	5/11	Fair
Yilmaz et al.,(167)	7/11	Moderate

Appendix 33: Ethical Approval: Rheumatologists' Perspectives regarding Eating and Swallowing Problems associated with Rheumatoid Arthritis in Adults with Temporomandibular Disorders

15/01/2019

Application Academic Year 2016/17

Applicant: MT32 Orla Gilheaney

Title of Research: Surveying the Perspectives of Rheumatology Healthcare Professionals regarding the Management of Oropharyngeal Dysphagia associated with Rheumatoid Arthritis-related Temporomandibular Disorders: An Irish Perspective.

Dear Orla,

Your revised submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Friday 16th December, and has been approved in full. We wish you the very best in your research activities.

Please note that on completion of research projects, applicants should complete the End of Project Report Form and submit one signed hard copy to the School Office as well as an electronic copy (slcsc@tcd.ie).

Best wishes,

Professor John Saeed

Chair, Research Ethics Committee

School of Linguistic, Speech and Communication Sciences

Appendix 34: Standardised Email: Rheumatologists' Perspectives regarding Eating and Swallowing Problems associated with Rheumatoid Arthritis in Adults with Temporomandibular Disorders

Dear healthcare professional,

My name is Órla Gilheaney. I am a full-time Ph.D. student at Trinity College Dublin. I am completing a survey on the perspectives of professionals working in Ireland with patients who have rheumatoid arthritis (RA)-related temporomandibular disorders (TMDs) and dysphagia. The survey is available on the following link:

https://www.surveymonkey.com/r/MPCBRFN

Responding to this survey is entirely optional. This study is being conducted as part of a larger study on the epidemiology and management of RA-related TMDs and dysphagia under the supervision of Dr. Margaret Walshe. This is a non-funded study.

Why are we doing this survey?

Temporomandibular/jaw joint problems caused by RA restrict the movement of the jaw, cause jaw pain and tiredness, and can cause the patient to experience oropharyngeal dysphagia. Little is known about the perspectives of rheumatology professionals working with patients presenting with oropharyngeal dysphagia caused by RA-related TMDs. I would like to invite you to take part in this research. The survey results will be written up as part of my final Ph.D. thesis and may be presented at conferences and published in relevant journals.

What do we expect from participants in the study?

We invite you to answer all the questions in this anonymous survey as honestly and clearly as you can. We anticipate it should take 5 minutes to complete the survey.

May you withdraw from the study?

Participation is completely voluntary. SurveyMonkey will accept responses until 3rd April 2017. SurveyMonkey provides responses as anonymous aggregates. Individual responses will not be retained.

Who approved this survey?

We have received ethical approval to conduct this survey from the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, TCD.

If you have any queries about the study, more information may be obtained from Órla Gilheaney via email (gilheano@tcd.ie) or Dr. Margaret Walshe via email (walshema@tcd.ie).

To access the survey, please click: https://www.surveymonkey.com/r/MPCBRFN

Kind regards and best wishes,

Órla Gilheaney.

Appendix 35: Survey: Rheumatologists' Perspectives regarding Eating and Swallowing Problems associated with Rheumatoid Arthritis in Adults with Temporomandibular Disorders

Question number	Question	Answer Options
1	What is your profession?	1. Rheumatologist 2. Medical physician 3. Medical scientist 4. Researcher 5. Other (please specify)
2	In what type of facility do you work?	1. Large university affiliated teaching hospital 2. Local/General non-teaching hospital 3. Third level academic institution 4. Nursing home 5. Rehabilitation centre 6. Community care 7. Private practice 8. Other setting (Please specify below)
3	How many years of clinical experience do you have?	1. None 2. <1 year 3. 1-5 years 4. 6-10 years 5. 11-15 years 6. >15 years
4	How significant do you think dysphagia is in TMD patients?	1. Not at all significant 2. Slightly significant 3. Significant 4. Fairly significant 5. Very significant
5	Do you have clinical experience in the management of patients with dysphagia and TMD? (If no, please proceed to the end of the survey).	1. Yes 2. No
6	What assessment methods do you routinely use for patients with TMD who report dysphagia?	1. I do not routinely assess for this 2. Subjective clinical examination 3. Dental examination 4. Self-report questionnaires 5. RDC/TMD protocol 6. Objective imaging assessment 7. Other
7	Do you agree/disagree with these statements? 1. I routinely assess for dysphagia in people with TMD 2. I use a specific assessment protocol with people with TMD and dysphagia 3. This assessment protocol differs based on the presence/absence of dysphagia 4. If dysphagia is suspected in a TMD patient I will refer the patient for videofluoroscopy 5. If dysphagia is suspected in a TMD patient I will refer the patient to appropriate team members	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
8	What treatment methods do you routinely use for patients with TMD who report dysphagia?	1. I do not routinely treat this 2. Compensatory techniques (e.g.: diet modifications) 3. Non-swallow exercise (e.g.: chewing exercises) 4. Swallow exercises (e.g.: effortful swallow) 5. Occlusal appliances 6. Surgery 7. Orthodontics 8. Relaxation techniques 9. Thermal packs

		10. Medications 11. Patient education and counselling 12. Other
9	Do you agree/disagree that the following outcomes are important when managing patients experiencing dysphagia and TMDs? 1. Improvement in swallowing 2. Improvement in chewing 3. Improvement in oral intake 4. Improvement in range of motion 5. Reduction of pain 6. Reduction of fatigue 7. Improvement in quality of life 8. Occlusal changes 9. Reduction of parafunctional habits (e.g.: bruxism) 10. Patient education 11. None of the above	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
10	Do you agree/disagree with these statements? 1. I am satisfied with available assessment methods used with TMD patients experiencing dysphagia 2. I am satisfied with available treatment methods used with TMD patients experiencing dysphagia 3. I am satisfied with the overall quality of care typically provided to TMD patients experiencing dysphagia	1. Strongly agree 2. Agree 3. Unsure 4. Disagree 5. Strongly disagree
11	Which professionals do you typically liaise with when managing patients with dysphagia and RA-related TMDs?	1. Not applicable 2. Dentist 3. Gastroenterologist 4. Medical physician 5. Rheumatologist 6. Neurologist 7. Surgeon 8. Nurse 9. Dietitian/ Clinical nutritionist 10. Speech and language therapist 11. Occupational therapist 12. Physiotherapist 13. Pharmacist 14. Engineer 15. Radiologist 16. Otolaryngologist 17. Medical scientist 18. Other (please specify)
12	Which professionals that you currently do not work with would you like to liaise with when managing these patients?	1. Dentist 2. Gastroenterologist 3. Medical physician 4. Neurologist 5. Surgeon 6. Nurse 7. Dietitian/ Clinical nutritionist 8. Speech and language therapist 9. Occupational therapist 10. Physiotherapist 11. Pharmacist 12. Engineer 13. Radiologist 14. Otolaryngologist 15. Other
13	Do you have any further comments that you would like to share on this topic?	

Appendix 36: Research Output

Published Journal Articles

1. Gilheaney, Ó., Zgaga, L., Harpur, I., Sheaf, G., Kiefer, L., Béchet, S., & Walshe, M. (2017). The prevalence of oropharyngeal dysphagia in adults presenting with temporomandibular disorders associated with rheumatoid arthritis: A systematic review and meta-analysis. *Dysphagia*, 1-14.
2. Gilheaney, Ó., Béchet, S., Kerr, P., Kenny, C., Smith, S., Kouider, R., ... & Walshe, M. (2018). The prevalence of oral stage dysphagia in adults presenting with temporomandibular disorders: A systematic review and meta-analysis. *Acta Odontologica Scandinavica*, 1-11.
3. Gilheaney, Ó., Stassen, L. F., & Walshe, M. (2018). The prevalence, nature, and management of oral stage dysphagia in adults with temporomandibular joint disorders: Findings from an Irish cohort. *Journal of Oral and Maxillofacial Surgery.*
4. Gilheaney, Ó., Kerr, P., & Walshe, M. (2018). The use of modified diets by adults with temporomandibular disorders: Systematic review and meta-analysis. Journal of the Irish Dental Association, 64(5); 249- 254.

Published Protocols

1. Gilheaney, Ó., Zgaga, L., Harpur, I, Kerr, P., & Walshe, M. (2016). Protocol: The prevalence of oropharyngeal dysphagia in adults presenting with temporomandibular disorders: A systematic review and meta-analysis. PROSPERO 2016:CRD42016050846. 2016. Retrieved from http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016050846 22nd July 2016.
2. Gilheaney, Ó., Harpur, I., Sheaf, G., Zgaga, L., & Walshe, M. (2016). Protocol: The prevalence of oropharyngeal dysphagia in adults presenting with temporomandibular disorders associated with rheumatoid arthritis: A systematic review and meta-analysis. Retrieved: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016033528. Date accessed: February 2016.

Oral Presentations

1. Gilheaney Ó., Stassen, L., & Walshe, M. (2017). "Surveying the prevalence and nature of oropharyngeal dysphagia experienced in adults presenting with temporomandibular disorders." RCSI National Audit / Presentation day, Dublin, Ireland, February 3rd 2017.
2. Gilheaney Ó., & Walshe, M. (2017). "Oropharyngeal dysphagia in temporomandibular disorders: Investigating an invisible illness." Irish Association of Speech and Language Therapists Conference, Dublin, Ireland, May 24th 2017.
3. Gilheaney Ó., & Walshe, M. (2017). "The prevalence, nature, and management of oropharyngeal dysphagia in adults presenting with temporomandibular disorders". TCD Clinical Speech and Language Studies Seminar, Dublin, Ireland, March 30th 2017.
4. Gilheaney Ó., & Walshe, M. (2017). "The prevalence, nature, impact, and management of oral stage dysphagia in adults presenting with temporomandibular disorders.". TCD Postgraduate Lecture for MSc students, Dublin, Ireland, January 25th 2018.
5. Gilheaney Ó., & Walshe, M. (2018). "Oral Stage Dysphagia in Adults Presenting with Temporomandibular Disorders." ESSD Conference, Dublin, Ireland, September 29th 2018.

Poster Presentations

1. Gilheaney, Ó., Zgaga, L., Harpur, I., Sheaf, G., Kiefer, L., Bechet, S., & Walshe, M. (2016).“The prevalence of oropharyngeal dysphagia in adults presenting with temporomandibular disorders associated with rheumatoid arthritis: Examining the evidence.” European Society of Swallowing Disorders Congress, Milan, Italy, October 14-15th 2018. *Dysphagia*, (32): 178.
2. Gilheaney, Ó., Zgaga, L., Harpur, I., Sheaf, G., Kiefer, L., Bechet, S., & Walshe, M. (2016).“The prevalence of oropharyngeal dysphagia in adults presenting with temporomandibular disorders associated with rheumatoid arthritis: Examining the evidence.” The Health and Social Care Professional Conference, Dublin, Ireland, November 16th, 2016.
3. Gilheaney Ó., Stassen, L., Zgaga, L., & Walshe, M. (2017). “Surveying the prevalence and nature of oropharyngeal dysphagia experienced by adults presenting with temporomandibular disorders.” RCSI SPHeRE conference, Dublin, Ireland, January 12th 2017.
4. Gilheaney Ó., Stassen, L., & Walshe, M. (2018). “”Eating is my worst nightmare”: The epidemiological investigation of oral stage dysphagia in adult patients with temporomandibular disorders”. European Society of Swallowing Disorders Congress, Barcelona, Spain, September 21- 22nd 2017. *Dysphagia*, (33): 104.
5. Gilheaney Ó., Stassen, L., & Walshe, M. (2017). “Patient contribution to the development of a novel educational tool for adults presenting with temporomandibular disorder-related oral stage dysphagia.” RCSI SPHeRE conference, Dublin, Ireland, January 12th 2018.

Journal Articles Prepared for Publication

1. Submission of manuscript for publication to the *Journal of the Irish Dental Association*: “*Oral stage dysphagia and temporomandibular disorders: Irish dental professionals’ perspectives on management.”* - Decision pending.
2. Submission of manuscript for publication To the *Irish Medical Journal*: “*Rheumatologists’ perspectives regarding oral stage dysphagia associated with rheumatoid arthritis-related temporomandibular disorders*.” - Decision pending.
3. Submission of manuscript for publication to the *Mediterranean Journal of Rheumatology*: “*Modified diet use in adults with temporomandibular disorders related to rheumatoid arthritis: A systematic review*.”- Decision pending.