EXPLORING TEMPOROMANDIBULAR DISORDERS

Longitudinal and Qualitative Perspectives

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Abstract

Background

Ideally, all clinical decision-making should enable care provision on the best available scientific evidence, clinical experience, and evaluated risks and benefits. Even though there are validated and evaluated decision tools for identification, diagnostics and treatment of temporomandibular disorders (TMD), patients with TMD still seem to go undetected, undiagnosed and undertreated in dentistry. Reasons for this discrepancy are unclear, but this clearly is a disadvantage for patients with TMD. Therefore, this project aimed to explore TMD in relation to the longitudinal course of the symptoms, dentists’ decision-making, and patients’ experiences.

Methods

The project was conducted at the Public Dental Health Services in the Region of Västerbotten, Northern Sweden. Data in the longitudinal studies were based on the screening instrument for TMD, the 3Q/TMD, and included self-reported orofacial pain and jaw dysfunction, specifically jaw catching/locking, from 2010 to 2017 (n=180,308; age 5-104). Descriptive statistics, generalized estimating equation models, and Poisson regression were used for analyses. Data included in the qualitative studies were the transcribed individual interviews with dentists (n=22, age 25-64) and patients (n=16, age 20-65). Analyses were based on the Grounded Theory and the Qualitative Context Analysis.

Results

The prevalence of orofacial pain increased over time (p<.01), but the prevalence of jaw catching/locking remained similar. The incidence, prevalence, and persistence of orofacial pain and jaw catching/locking were significantly higher in women than in men (p<.01). Women were at a higher risk for reporting both the first onset and the persistent orofacial
pain (IRR 2.37; 95% CI, 2.25-2.50 and IRR 2.56; 95% CI, 2.28-2.87, respectively), and jaw catching/locking (IRR 2.29; 95% CI, 2.11-2.49 and IRR 2.32; 95% CI, 2.04-2.63, respectively) when compared to men. The onset of pain or jaw catching/locking was mostly independent and exclusive, i.e. without the other symptom (84.1%), and was higher for orofacial pain (64.9%) than for jaw catching/locking (19.2%). The decision-making process in the management of TMD was illustrated as an interplay between internal and external elements, where the dentists wished to apply professional knowledge but identified organizational obstacles and lack of self-confidence in their clinical decision-making for TMD. The patients expressed worry and social discomfort as a consequence of TMD. However, they strived to deal with the symptoms on their own as long as possible before seeking help. The challenges to access dental care and to receive suitable management were acknowledged. The right care at the right time was identified more like a wish than a current state of perceived TMD management.

Conclusions

The observed longitudinal patterns of orofacial pain and jaw dysfunction indicate increasing prevalence of orofacial pain together with substantial gender differences in TMD. The finding of independent onset of jaw catching/locking and orofacial pain reinforces that these two differ in the pathophysiology. The challenges in decision-making for patients with TMD and perceived suboptimal management of TMD symptoms are partly related to the structural organization of the Public Dental Health Services. Thus, careful review of the current organization is warranted since the treatment-need related to orofacial pain will probably increase.

Keywords: cohort studies, decision-making, dental health services, dentistry, epidemiology, evidence-based dentistry, facial pain, population health, qualitative studies, temporomandibular joint disorders, women.
Abbreviations and definitions

3Q/TMD – three validated screening questions for frequent temporomandibular disorders

CI – confidence interval

DC/TMD – diagnostic criteria for temporomandibular disorders

EBM – evidence-based medicine

GEE – generalized estimating equations

GT – grounded theory

Incidence – proportion or rate of new cases in a defined population during a particular time period. Incidence rate describes how quickly the incident occurs over a specified period of time

IRR – incidence rate ratio – ratio of two rates of incidence

OR – odds ratio or probability – the strength of the association between two events

PDHS – public dental health services

Prevalence – proportion of cases in a defined population at or during the particular time period

RDC/TMD – research diagnostic criteria for temporomandibular disorders

QCA – qualitative content analysis

SDM – shared decision-making

TMD – temporomandibular disorders

TMJ – temporomandibular joint
Enkel sammanfattning på svenska

Bakgrund

Smärta och funktionsstörning i käksystemet (Temporomandibular disorders - TMD) inkluderar muskuloskeletala tillstånd i käkmuskulaturen, käkleden och associerade strukturer. Förekomsten av TMD i den vuxna befolkningen beräknas vara omkring 10%. Tillståndet ökar i prevalens i tonåren och är vanligare bland kvinnor än män. Funktionsstörning i käksystemet avser gap- och tuggsvårigheter och kan uppträda som ett ensamt symtom eller tillsammans med smärta. Smärta associerad med TMD är en av de vanligaste kroniska smärtorna i befolkningen och den vanligaste orsaken till kronisk smärta som behandlas inom tandvården. Kronisk smärta har en negativ effekt på den drabbades livskvalitet och tidiga interventioner är därför viktiga för att förbättra den långsiktiga prognosen.


Metod

Projektet omfattar två longitudinella kvantitativa studier och två kvalitativa studier. För de longitudinella forskningsfrågorna användes patientsvar till ett screeningsinstrument för TMD - 3Q/TMD som samlades in på Folktandvården och sparades i ett lokalt tandvårdsregister i Region Västerbotten. Kohorten bestod av 180,308 unika individer och

Resultat


Slutsats

Sammantaget visar resultaten könsskillnader i incidens, prevalens och långvarighet av både orofacial smärta och funktionsstörningar i käksystemet samt indikerar patofysiologiska skillnader mellan dessa
tillstånd. Resultaten pekar också mot en förbättringspotential av tandvårdens rutiner för omhändertagandet av patienter med TMD.
Original papers


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Background

Temporomandibular disorders

Epidemiology

Temporomandibular disorders (TMD) is the term embracing pain and dysfunction involving the temporomandibular joint (TMJ), masticatory muscles, and associated structures (Dworkin and LeResche 1992; LeResche 1997). The etiology of TMD is multifactorial and is often discussed with regard to a biopsychosocial model (Engel 1977; Suvinen et al. 2005). This conceptual model comprises biological, psychological, and social factors (Figure 1) contributing to the development of musculoskeletal disorders and pain, including TMD. These factors can also be divided into predisposing, initiating and perpetuating depending on their role in the condition’s development (McNeill 1983).

![Diagram of factors involved in TMD](image)

*Figure 1. Factors involved in the onset and development of TMD according to the biopsychosocial model for the etiology.*
The pathophysiology of TMD is not completely clear and research is ongoing. The pathophysiology of the pain related to TMD has been discussed in terms of neurological alterations (Smith et al. 2013), endocrine changes (Diatchenko et al. 2005), and inflammation pathways (Slade et al. 2011), whereas joint-related jaw dysfunction has been interpreted through the structural re-arrangements and mechanical factors (Okeson 2012; Palla 2016). The pathophysiologic pathways for TMD also take into account the psychosocial variables since the perception of pain or dysfunction is an interplay between affective, cognitive, and nociceptive centers in the brain (Dubner and Ren 1999). Thus, the individual perception of tissue damage, or potential tissue damage, is also affected by emotions and behavior.

The annual incidence of TMD is 4% in adults, and with no significant gender difference (Sanders et al. 2013). The prevalence of TMD ranges between 5-12% in adults in the general population, and affects women twice as often compared to men (Isong et al. 2008; Lövgren et al. 2016a; Manfredini et al. 2011). The gender differences are minimal in childhood, but from adolescence women start to dominate (Köhler et al. 2009; Lövgren et al. 2016a; Nilsson et al. 2005). The reasons for these gender differences are not completely clear, but some theories exist that include estrogen impact on TMD development (LeResche et al. 1997; Yadav et al. 2018), women seeking care at a greater extent (Kuttila et al. 1997; Thompson et al. 2016), greater health awareness in women than men (Ek 2015), and more prevalent chronic pain among women than men (Macfarlane et al. 2001). The gender similarities in incidence but differences in prevalence may indicate a higher persistence of the symptoms in women than in men as well as lower recovery rates in women.

Longitudinal studies on TMD development and persistence have demonstrated remittance rates of nearly 50% in the case of pain related to TMD after a five-year follow-up (Ohrbach and Dworkin 1998), and roughly 33% after an eight-year follow-up (Kapos et al. 2018). Thus, a substantial number of patients with TMD experience transition from acute to chronic pain. In acute pain, noxious stimuli induce a signal that is transported by first-order neurons to the brain stem. Here, neurotransmitters activate second-order neurons, and the signal is
transported further, resulting in its interpretation in the cortex. Persistent pain activates secondary mechanisms both in the periphery and in the central nervous system. In the periphery, this starts with sensitization of the first-order neurons by upregulation of neurotransmitters and continues with sensitizing second-order spinal neurons (Rajandram et al. 2022). Both environmental and genetic factors also play a substantial role in this process (Slade et al. 2016). Therefore, the pathophysiological mechanisms are not completely clear, but some similarities between chronic orofacial pain and chronic body pain have been acknowledged, e.g. central sensitization (Sessle et al. 2021), physical comorbidities and negative psychosocial states (Velly et al. 2014), and individual variability in symptoms, course, and treatment outcomes (Diatchenko et al. 2013).

**Symptoms and clinical signs of TMD**

Pain and fatigue in the jaws and face, and clicking, catching and locking in the TMJ are some of the symptoms reported by patients with TMD. Pain is defined as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (International Association for the Study of Pain 2020). In dentistry, acute pain in the orofacial area is often caused by toothache, whereas chronic pain is most commonly related to TMD (Lipton et al. 1993). In addition, pain related to TMD is also one of the most frequent chronic pain conditions after back, neck, and knee pain (Breivik et al. 2006). Although acute pain has a warning role in protection of the tissues, chronic pain lacks this quality. Chronic pain is no longer only a signal of an actual or potential tissue damage, but a condition affecting the central nervous system (DeLeo and Winkelstein 2002) and is associated with a negative impact on individual’s psychosocial health (Turk et al. 2016). The theoretical distinction between acute and chronic pain is based on pain duration. Therefore, all patients with chronic pain have first experienced acute pain, but not all have developed chronic pain. Catastrophizing, psychosocial stress, somatic awareness, negative personality, somatization, widespread pain, and comorbidities are all considered as risk factors to develop the chronicity (Fillingim et al. 2013; Maixner et al. 2011; McBeth et al. 2001; Slade et al. 2007).
The most common TMD-pain condition is myalgia (Schiffman et al. 2014) that can be isolated or exist together with other symptoms and clinical signs of TMD. For example, pain can lead to jaw dysfunction since pain itself can limit jaw movements, refer to adjacent tissues, or have kinesiophobic consequences.

Jaw dysfunction includes difficulties performing daily jaw activities such as chewing, opening the mouth, brushing the teeth, and yawning. Such jaw functional limitations can, among others, be a consequence of orofacial pain, joint-related conditions, muscle- or skeletal diseases, or neurological impairment.

The most common symptom of TMD is TMJ clicking, or in clinical terms disk displacement with reduction (Manfredini et al. 2011). Disk displacement with reduction is frequently found in non-patient populations and is considered more as an anatomical variation than a pathology (Turp et al. 2016; Valesan et al. 2021). However, some other joint-related conditions like jaw locking and catching can lead to difficulties in daily jaw activities, e.g. chewing or jaw opening (Ohrbach et al. 2008).

In addition to a negative effect on an individual’s physical health, TMD has a negative impact on an individual’s oral health-related quality of life (Dahlström and Carlsson 2010; Suvinen et al. 2005). Higher levels of catastrophizing (Häggman-Henrikson et al. 2021), avoidance behaviors (Häggman-Henrikson et al. 2022), and anxiety and depression (Gatchel et al. 1996) are observed in patients with TMD. The chronic nature of the condition (Maixner et al. 2011) and common comorbidities (Ohrbach et al. 2011; Sanders et al. 2013) along with related sick-leaves (Kuttila et al. 1997; Salinas Fredricson et al. 2022) not only have negative impact on the individual but is also a socioeconomic burden on society (Maixner et al. 2011). Psychosocial factors have been highlighted previously (Breivik et al. 2006) and are of importance for the evaluation and management of TMD as well as for the assessment of the prognosis.
Management of TMD

In Sweden, the treatment need for TMD varies between 5 and 15% (National Board for Health and Welfare 2018), and is estimated to be similar internationally (Al-Jundi et al. 2008). However, available statistics from Sweden show that only 0.5 to 1.5% of these patients receive treatment related to TMD in the dental care system (National Board for Health and Welfare 2018). However, the majority of patients with TMD can be effectively treated within primary dental care and can thereby avoid the transition from acute to chronic condition (Macfarlane 2016). Early interventions show significant results in the reduction of pain, improvement in coping strategies, and reduction of emotional distress when compared to a non-intervention group (Gatchel et al. 2006). Nearly 80% of individuals with early-onset TMD may expect positive treatment outcome (Mortazavi et al. 2010). In addition, early biopsychosocial interventions were shown to reduce jaw-related health care expenditures when compared to a non-intervention group (Stowell et al. 2007). Hence, early interventions are suggested to be important in order to prevent a chronic course of the TMD symptoms (Macfarlane 2016) and to be a cost-effective long-term solution (Stowell et al. 2007).

To easily identify patients who could benefit from a further TMD examination and by that also enable early interventions, a validated screening instrument – the 3Q/TMD (Lövgren et al. 2016b), was introduced in Sweden in 2010. For diagnostics of the most common TMD conditions, there is an internationally adopted and accepted diagnostic instrument – the Diagnostic Criteria for Temporomandibular Disorders, the DC/TMD, that includes a standardized examination of the jaw system together with a diagnostic algorithm (Schiffman et al. 2014). The National Guidelines for Dental Care in Sweden is another support instrument with the intention to facilitate the decision-making with regard to management of different dental conditions, including TMD (National Board for Health and Welfare 2021). Such support instruments – for identification, diagnostics and treatment of TMD, are a part of the Evidence-Based Medicine (EBM) model. Ideally, all clinical decision-making should be based on EBM to enable care provision based on the best available scientific evidence, clinical experience, and evaluated risks and benefits (Craig et al. 2001; Sackett 1997b).
As mentioned in the previous paragraph, the 3Q/TMD is a validated screening instrument for the detection of possible TMD (Lövgren et al. 2016b). The 3Q/TMD consists of three dichotomous (Yes/No) screening questions that are formulated as follows:

Q1: Do you have pain in your temple, face, jaw, or jaw joint once a week or more?
Q2: Do you have pain once a week or more when you open your mouth or chew?
Q3: Does your jaw lock or become stuck once a week or more?

The questions were introduced in the Public Dental Health Services (PDHS) to provide a clinical guidance that patients could benefit from a further examination of the jaw system. The first two questions cover self-reported frequent orofacial pain and frequent pain on jaw function, and the third question relates to jaw dysfunction, specifically catching/locking. Initially, the first two questions were validated in accordance to the Research Diagnostic Criteria for TMD (RDC/TMD) (Nilsson et al. 2006), and the third question was face-validated (consensus decision) by an expert group. Later, all three questions were validated in accordance with DC/TMD (Lövgren et al. 2016b). The screening questions showed high validity for TMD pain diagnoses and fair to moderate validity for intra-articular diagnoses (Lövgren et al. 2016b). The National board for health and welfare in Sweden recommends the use of the 3Q/TMD to screen all dental patients starting at the age of 12 (National Board for Health and Welfare 2021).

DC/TMD

DC/TMD is a diagnostic instrument that enables a standardized clinical examination of the jaw system; it was introduced in 2014 as a clinically friendly diagnostic instrument evolved from the previously used RDC/TMD (Schiffman et al. 2014). There are different levels of the DC/TMD depending on the specific needs of the dental practitioner and
the dental setting. In general, this instrument consists of two axes allowing both clinical and psychosocial evaluations. Furthermore, the DC/TMD diagnostics follows a standardized decision tree/algorithm leading to the most common TMD-pain diagnoses – myalgia, arthralgia, and headache associated to TMD, and the most common intra-articular diagnoses – disk displacement with reduction, disk displacement without reduction, and degenerative joint disease. Patient reported outcomes are incorporated into the diagnostic procedure both in the physical examination of the jaw system and in the evaluation of the psychosocial variables. For the evaluation of the psychosocial variables, e.g. anxiety, depression, and somatization, validated instruments are used. Such comprehensive evaluation benefits the clinical assessment of TMD (Visscher et al. 2018).

**Swedish National Guidelines for Dental Care**

Swedish national guidelines for dental care were first published in 2011 and updated in 2021 (National Board for Health and Welfare 2021). The guidelines contain dental care recommendations for the different dental conditions, including TMD. The recommendations are based on available scientific research and consensus decisions by experts in the specific dental areas. The intention of the guidelines is not only to guide the dental practitioner, but also to guide policy makers in the allocation of the dental resources in regard to the societal needs. The guidance for a specific condition is visualized as a scale ranging from 1 to 10, where a lower number indicates a higher priority of the treatment modality in relation to the risks and costs. The scale also includes a ‘do not do’ if the treatment modality is considered to result in a poor effect or even to be harmful, and ‘in the research setting’ if the treatment modality should not be used in a daily routine. The guidance scale also has an adjacent recommendation. Every recommendation includes a motivation in accordance with scientific research and/or consensus of an expert group in a specific dental area, and a health economic analysis.
Decision-making

Process of decision-making

The process of decision-making has been an interesting topic for a long time. Even though there are many models explaining the process of decision-making, all of them have their own strengths and weaknesses, a common integration of the dual process theory (Wason and Evans 1974) is present in almost all of them. The dual process theory explains the process of decision-making in regard to an implicit and an explicit. In other words, some of the decisions are made automatically, whereas others are made in an analytical way. In static circumstances, an easy decision, based on previous experiences and knowledge, would be made automatically – intuitively; a more complex decision requires a systematic review of the details – analytical manner. However, in the real world, the situations are often dynamic and an interplay between the intuitive and analytical manners in decision-making exists (Rusou et al. 2013). Furthermore, such a rational decision-making process is usually affected by other factors impeding or facilitating the process (Hajjaj et al. 2010). The construct of emotions has been identified as an important part of human decision-making. Loewenstein and Lerner describe that emotions can be divided into two major clusters – expected emotions and immediate emotions, depending on how they enter the decision-making process (Loewenstein and Lerner 2003). The expected emotions work still as rational inputs in addition to the dual process in decision-making. The expected emotions are predictions of the emotional outcome of the decision. These emotions usually influence an individual to select a decision that is related to a more positive emotional outcome. The immediate emotions are experienced at the time of the decision-making. These emotions are unpredictable. Depending on the nature of the immediate emotions, they may change the evaluation of the situation as well as the final decision to the better or to the worse (Loewenstein and Lerner 2003). More precisely, decision-making in relation to emotions is affected by the changes in a content of thought, a depth of thought, and a content of implicit goals. Therefore, the effect of a specific emotion onto a specific decision depends on interactions between the cognitive and motivational mechanisms triggered by each emotion (Lerner et al. 2015).
Clinical decision-making

Clinical decision-making is a problem-solving process in clinical practice starting from the first meeting with the patient. The clinical decision-making comprises the decision about what the patient is suffering from (diagnostics) and the decision about how to solve the patient’s problem (treatment). The intuitive and analytical patterns are used interchangeably through the steps of data collection, description, selection, inference, synthesis, and verification (Higuchi and Donald 2002; Hoffman 2007). Specifically in healthcare, the clinical situations can be very different and affected by clinical and non-clinical factors. For example, routine examinations are commonly predictable and here decisions are made mostly in accordance with the familiar and recognizable pattern. In emergency clinics, time pressure and unforeseen clinical situations are common. Some of the situations will probably be familiar and recognizable (here, we also have a factor of the clinician’s experience level), but will also require a new analytical evaluation ‘here and now’. So, even though the decision-making usually follows a predominant pattern, both clinical and non-clinical factors affect this process (Hajjaj et al. 2010). In dentistry, several factors affecting the decision-making process of the dentist have been identified previously. These include age, experience, finances (Ghoneim et al. 2020), gender (Lövgren et al. 2018a), individual preferences, sociodemographic situation (Kay and Nuttall 1995), and emotions (Kozlowski et al. 2017) that may lead to the biased decisions.

Evidence-based decision-making

In healthcare, including dentistry, the clinical decision-making process should ideally be evidence-based. EBM incorporates scientific evidence, clinical experience and patients’ values in daily clinical management (Craig et al. 2001; Sackett 1997b). Application of the EBM in clinical practice is often explained by the five-step EBM model (Figure 2) that includes converting information needs into answerable questions, finding the best evidence to answer these questions, critically appraising the evidence, applying the results into the clinical practice, and evaluating the
performance (Akobeng 2005). Even though the five steps seem to be an extensive process for decision-making, usually it takes only a few moments for the clinician to go through these steps in the clinical situation. This is based on previously described intuitive and analytical thinking patterns that allow us to evaluate every situation partly based on our knowledge and previous experiences (Wason and Evans 1974).

Figure 2. The five-step EBM model.

Decision instruments and guidelines are a part of EBM and are suggested to improve evidence-based decision-making (Craig et al. 2001), and thereby also improving quality of care. However, despite the existence of guidelines, EBM can be difficult to implement in the clinical setting because of the nature of the healthcare system, patients’ expectations, and the healthcare personnel themselves (Cheng et al. 2017; Hannes et al. 2005; Spallek et al. 2010). Furthermore, evidence-based guidelines or routines are not always applicable in a given situation, thus requiring individual evaluation and probably individual adaptation (Hasson and von Thiele Schwarz 2017).

Decision-making in the management of TMD

Clinical decision-making for the management of TMD in dentistry should also embrace treatments with verified efficacy and emphasize patient-centered care, in agreement with EBM (Craig et al. 2001; Sackett 1997a). However, dentistry faces similar barriers as other healthcare areas that affect decision-making and complicate the implementation of EBM; these include lack of physical infrastructure, time resources, and individual interest (Gigerenzer and Gaissmaier 2010; Hajjaj et al. 2010). Clinical decision-making for TMD is no exception for this (Al-Baghdadi et al. 2019; Kao 2011). One such example from Swedish dental care is the
implementation of the 3Q/TMD. Despite this implementation, nearly half of the patients with TMD received no clinical decision by their dentists (Näsström et al. 2019). However, the reasons for the lack of incorporation of EBM in managing TMD in dentistry are not fully understood. For example, it is not known what elements affect the individual dentist’s decision-making process. What are the facilitators and impeders of this process? There is also a lack of knowledge about how dentists perceive their day-to-day TMD-related clinical work with regard to personal and clinical skills, individual interests, workload and demands.

Patient-centered care

The previously predominant paternalistic model of clinical decision-making (Komrad 1983) has systematically been replaced by the patient-centered care model (Chin 2002). The patient-centered care is a key component of the EBM even though there have been early concerns of diminishing the use of the scientific evidence from the population research while focusing primarily on the individual patient needs (Guyatt et al. 2004). The Institute of Medicine defined care that is patient-centered as “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine Committee on Quality of Health Care 2001). Patient-centered care has been explored in healthcare settings and suggested as beneficial to patients since it is related to patient’s satisfaction and the treatment outcome (Epstein and Street 2011; Kuipers et al. 2019). In dentistry, patient-centered care regards care delivery through the good communication, encouragement, empowerment, and accentuating own responsibility in the process of decision-making, which is in line with the principles of patient-centered care (Epstein and Street 2011). However, the empirical assessment of it is not completely clear and a paucity of good quality research studies in the area has been identified (Scambler et al. 2016). In addition to this model, identifying the clinicians’ position, we still do not know the patients’ subjective role in their own decision-making regarding TMD. How do patients perceive their TMD symptoms and when do they decide to seek help? What are the patients’ thoughts about the contact with the dental healthcare professionals
regarding TMD? What role do the patients have in the decision-making for TMD management?
Rationale for this thesis

TMD is common in the general population (Lövgren et al. 2016; Manfredini et al. 2011; Schiffman et al. 2014), thus management of patients with TMD is a part of a dentist’s daily work. Everyday clinical practice is a continuous sequence of decision-making that affects the patients and the healthcare system on the whole. In the light of EBM, it is important that the treatment strategies are based on scientific evidence in order to create optimal routines for patients' clinical care. Even though there are EBM-based decision instruments for the identification, diagnostics, and treatment of TMD, patients with TMD still seem to go undetected, undiagnosed and undertreated in dentistry. The reasons for this discrepancy are unclear, but this clearly is a disadvantage for the patients with TMD.

Besides the negative physical consequences of TMD, TMD also impairs the affected individual’s quality of life, with substantial personal and societal costs. Because of this, the current undertreatment has a negative impact on both the individual and society. This stresses the importance of exploring the natural course of TMD, and to deepen our understanding of the decision-making process in the management of TMD in dentistry. Longitudinal studies from the general population may provide such crucial information about the expected development of TMD over time. This allows us to get a better understanding for assessment and prognosis of the condition. From a clinical point of view, more knowledge about the nature of TMD and the decision-making process in the management of TMD can hopefully move us a step closer to understanding the reasons for TMD undertreatment and to forecast the future development of it, and eventually to construct a strategy to improve the current situation.
Objective

The overall aim of the project was to explore temporomandibular disorders in relation to the longitudinal course of the symptoms, dentists’ decision-making, and patients’ experiences.

Specific aims

**Paper I**
To analyze the incidence, prevalence and chronification over time of orofacial pain related to TMD over an 8-year period in a large population sample.  
**Hypotheses:** the prevalence of orofacial pain is stable over time; the prevalence and incidence of orofacial pain is higher in women than men.

**Paper II**
To evaluate the incidence, prevalence and gender differences in jaw catching/locking over time and in relation to orofacial pain in the general population.  
**Hypotheses:** jaw catching/locking is more frequent in women than in men; the onset of jaw catching/locking is predominantly concurrent with the onset of orofacial pain.

**Paper III**
To explore the patients’ experiences of their TMD and related treatment.

**Paper IV**
To explore the decision-making process in the management of patients with TMD by general dental practitioners, and in doing so to conceptualize the clinical decision-making process in dentistry.
Participants and Methods

The project comprises studies of both quantitative and qualitative designs in order to investigate the research question. The utilization of different designs and scientific approaches allows a more comprehensive evaluation of a phenomenon. This project involved data from patients and dentists in the county of Västerbotten, Sweden. Table 1 provides an overview of the study designs, participants and methods used.

Context of the project

In Sweden, dental care is provided by the Public Dental Health Services (PDHS) and by private practitioners. Dental care is subsidized by the government, regardless of whether the patient visits a PDHS or a private dental practitioner. Dental check-ups are performed by dentists or by dental hygienists. Approximately 80% of the Swedish population have routine dental check-ups regularly. The rest of the population who do not have routine dental check-ups regularly often have socioeconomical difficulties and general health issues (National Board for Health and Welfare 2018). The frequency of routine dental check-ups depends on the individual dental health as determined by the dentist. Usually, it is every year, or every second, or third year. In the Region of Västerbotten, during the routine dental check-up, patients answer a mandatory digital health declaration, including the 3Q/TMD.

The Region of Västerbotten consists of almost 270,000 inhabitants, and of these, 70% have their routine dental check-ups regularly. More than half of these routine dental check-ups (54%) are performed at the PDHS (National Board for Health and Welfare 2018). There are roughly 8,000 general dental practitioners in Sweden (57% female) and one-third are in the age group of 55 to 64 years. There are approximately 70 specialists in TMD in the country. In Västerbotten, there are around 250 general dental practitioners (56% female) with fewer than 10 specialists in TMD (National Board for Health and Welfare 2019).
## Overview

*Table 1. Overview Studies I – IV.*

<table>
<thead>
<tr>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td><strong>Orofacial Pain</strong></td>
<td><strong>Jaw Dysfunction</strong></td>
<td><strong>Clinical Perspectives</strong></td>
</tr>
<tr>
<td>To analyze the incidence, prevalence and chronification over time of orofacial pain related to TMD over an 8-year period in a large population sample</td>
<td>To evaluate the incidence, prevalence and gender differences in jaw catching/locking over time and in relation to orofacial pain</td>
<td>To explore the patients’ experiences of their TMD and related treatment</td>
<td>To explore the decision-making process in the management of patients with TMD by general dental practitioners, and in doing so to conceptualize the clinical decision-making process in dentistry</td>
</tr>
<tr>
<td><strong>Design</strong></td>
<td>Register study of longitudinal design Cohort</td>
<td>Qualitative</td>
<td>Qualitative, Grounded Theory</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>Patients from the Public Dental Health Services in the Region of Västerbotten during 2010-2017</td>
<td>Purposive sampling from the patients examined at Public Dental Health Services in the Region of Västerbotten March - November 2019</td>
<td>Purposive sampling from the clinically active general dental practitioners at the Public Dental Health Services and Private Practices in the Region of Västerbotten 2018-2019</td>
</tr>
<tr>
<td></td>
<td>Local dental register</td>
<td>n=16</td>
<td>n=22</td>
</tr>
<tr>
<td><strong>Data</strong></td>
<td>- Orofacial pain: Q1 and Q2 from the 3Q/TMD - Age - Gender - Calendar year - Clinics</td>
<td>- TMD: Q1, Q2 and Q3 from the 3Q/TMD - Birth year - Gender - Calendar year</td>
<td>Transcriptions including answers to: How? What? Why? When? and regarding: TMD complaints Treatment Decision-making Screening questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Transcriptions including answers to How? What? Why? When? and regarding: Role of dentistry Decision-making Patients with TMD Screening for TMD</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>- GEE - Poisson regression</td>
<td>- GEE - Poisson regression</td>
<td>- Qualitative Content Analysis</td>
</tr>
</tbody>
</table>
Quantitative methods (Studies I and II)

Study setting and participants

Data on the individuals’ answers to the 3Q/TMD were collected from all PDHS in the Region of Västerbotten, Sweden from 2010 to 2017. All individuals aged five or older, who had undergone a routine dental examination at PDHS in Västerbotten during 2010-2017 and had a completed digital health declaration together with the 3Q/TMD were included in the studies (Figure 3). Exclusion criterion was having a temporary personal identity number, since a temporary residency permit would make those individuals’ follow-ups impossible.

In total, 180,308 individuals (equal gender distribution) were examined in 525,707 dental examinations (median age at examination: 29.0 years, IQR 13 years), with a median number of three examinations per individual over the study period. Individuals with an affirmative answer to at least one of the 3Q/TMD were classified as individuals with TMD, i.e. 3Q-positives; whereas individuals with negative answers to all three questions were classified as controls, i.e. 3Q-negatives. In this project, individuals with affirmative answers to the first two screening questions were classified as cases with orofacial pain. Individuals with an affirmative answer to the third screening question were classified as cases with jaw dysfunction, specifically catching/locking.

For the evaluation of the incidence and longitudinal course of TMD, repeated data were used annually over the 8-year period and only individuals with no self-reported TMD at their first dental check-up were included. The symptoms were considered as “persistent” if the individuals had at least two consecutive positive reports of pain or jaw catching/locking in a 4-year period. For the evaluation of the onset of TMD, individuals with no self-reported TMD at their first dental check-up and with at least two further dental check-ups during the study period were included. On the first report of orofacial pain, jaw catching/locking or both, individuals were recategorized as cases with the onset of TMD. These cases were followed until their last dental check-up and the
following symptoms were recorded: independent onset of orofacial pain or jaw catching/locking, concurrent onset of orofacial pain and jaw catching/locking, a first onset of orofacial pain and a later onset of jaw catching/locking, or a first onset of jaw catching/locking and a later onset of orofacial pain.

Figure 3. Flow-chart over the inclusion of the study populations for Studies I and II. The same cohort contributed to both longitudinal studies.
Statistical analyses

Data analyses were performed using the statistical software IBM SPSS Statistics for Windows (Version 28) and R v.3.5.3 (R Core Team 2019). Descriptive statistics were used to characterize the study populations and to estimate the relationship between the onset of orofacial pain and jaw catching/locking. The cohort and sub-cohorts were characterized by the number of available examinations per individual, and the median and interquartile range of age at first visit. Generalized estimating equations (GEE) models with logit link function were used to analyze the prevalence of TMD, with age as an independent variable. Age was modeled using natural cubic splines with five knots at the 16.7th, 33.3rd, 50th, 66.7th, and 83.3rd percentiles of the study population’s age distribution. A previous study on the prevalence of TMD over the lifespan has shown a non-linear relationship between age and prevalence (Lövgren et al. 2016); therefore, a spline regression terms were included in the model for evaluation of the risk for TMD in this project. Splines is a method for fitting smooth regression lines to allow creation of a statistical model for a non-linear relationship between age and prevalence of TMD. The models were also fitted on the full cohort, including gender as a factor, as well as stratified by gender.

Incidence rates for the first onset and persistent TMD were calculated as a ratio between the number of new cases during the follow-up period and the total number of person-years at risk (only the years when a person attended routine dental check-up and completed the 3Q/TMD). Incidence rate ratios between women and men were calculated using Poisson regression and adjusted for age at the first dental examination employing natural cubic splines with three knots at the 10th, 50th, and 90th percentiles. Odds ratios were presented with 95% confidence intervals. The significance level was set at 0.05.
Qualitative methods (Studies III and IV)

Study setting and participants

The qualitative approach for this part of the project was chosen in order to explore the processes, perceptions and experiences from the different perspectives in the area of TMD. The participants, dentists and patients, for both studies were recruited at the dental clinics in the Västerbotten. Purposive samples were taken from two relevant populations (patients and dentists) based on maximum variation sampling (Graneheim and Lundman 2004), and covered the following:

- The geographic and sociodemographic parts of the Region of Västerbotten;
- Both women and men;
- Different ages;
- Diversified professional experience among dentists, e.g. time since graduation;
- Diversified TMD symptoms among patients, e.g. orofacial pain and jaw dysfunction.

For the study on patients’ experiences of TMD and related treatment (Study III), participants were recruited by using purposive sampling with maximum variation from the local dental register at PDHS in the Region of Västerbotten during March – November of 2019. In total, 22 individuals aged 18 or older who reported orofacial pain (affirmative answers to Q1 and Q2) or jaw catching/locking (affirmative answer to Q3) at their latest dental check-up at the PDHS were invited to participate. The first contact was made by a standardized letter with information about the study. Later, a telephone contact was established, and more detailed information about the study was provided. If an individual was interested in participating, the interview location and date were arranged. Sixteen individuals agreed to participate in the study. Written informed consent was obtained from all participants. Participation was on a voluntary basis.
For the Study IV, the dentists, both women and men from the PDHS and private dental clinics covering all geographic areas of the Region of Västerbotten were invited to participate in an hour-long interview. The first contact was made by standard e-mail invitation during the 2018 – 2019. The dentists who were interested in participating replied by e-mail, and a time for the interview was scheduled in accordance with the participant’s preferences. Written informed consent was obtained from all participants. All participation was on a voluntary basis.

Data collection

Data collection was performed by using semi-structured, one-on-one interviews according to pre-tested, semi-structured interview guides and mind maps (Kvale and Brinkmann 2009) (Figure 4). The mind map for the interviews with the patients covered two main themes, i.e. decision-making and treatment, and was placed in front of the participant as guidance for the interview. The interview guide included open-ended questions such as: ‘Could you please tell me about your symptoms in your jaws’; ‘When and why did you decide to seek help for your jaw-related problems?’; and ‘What are your experiences with the treatment of your symptoms?’ and was used as a support-tool for the interviewer. Each interview lasted approximately 30 minutes. All participants in the Study III were clinically examined in accordance with the DC/TMD criteria. This clinical examination allowed us to evaluate the presence of clinical signs of TMD and to enrich the description of the study sample. But more importantly, it rewarded the participants with an opportunity to receive a qualified clinical examination and an individual discussion about management possibilities.

The mind map for the interviews with the dentists (Study IV) covered two main themes, i.e. decision-making and the role of dentistry, and was also placed in front of the participant as guidance for the interview. The interview guide included open-ended questions such as: ‘How would you describe the role of the dental care organization for this patient group?’; and ‘How do you make your decisions as a clinician?’, and was used as support-tool for the interviewer. Each interview lasted for approximately
45 minutes. The data collection process for the Study IV was guided by the principles of Grounded Theory by Charmaz (Charmaz 2014). Therefore, the emergent study design and constant comparisons were in focus already during the interviewing process and the interviewing continued until the theoretical saturation (Saunders et al. 2018). All the interviews were recorded, transcribed verbatim, and later checked for accuracy.

**Figure 4.** The synthesis of the mind maps used in the qualitative studies. Role of dentistry and Decision-making were the main topics for the interviews with the dentists (Study IV), and Treatment and Decision-making were the main topics for the interviews with the patients (Study III). The main topics consisted of more specific discussion areas as illustrated.

Data analysis

Qualitative Content Analysis

Qualitative Content Analysis (QCA) is a suitable method to study experiences, perspectives and opinions of the participants, enabling to elucidate manifest and latent content (Graneheim and Lundman 2004) and was therefore used for the data analysis in the Study III. The analysis followed the principles of QCA by Graneheim and Lundman (Graneheim
and Lundman 2004). Firstly, the transcriptions were coded independently by two calibrated co-authors. Secondly, the codes were discussed and sorted into sub-categories, and then into categories depending on the context (Table 2). Later, all authors discussed the findings and shared their interpretation of the findings. Finally, the authors agreed on one theme, four categories, and eight sub-categories.

The Grounded Theory

Grounded Theory (GT) is useful especially when studying a process (Corbin and Strauss 2008), and as in this case the process of clinical decision-making in Study IV. The analysis followed the principles of GT by Charmaz (Charmaz 2014) and was performed in parallel to data collection. The transcribed data were divided into meaning units and then subsequently independently coded by two calibrated co-authors. Codes were interpreted and compared for differences and similarities, and then sorted into sub-categories and categories depending on the message they bared (Table 3). The two authors discussed the codes, sub-categories and categories regularly to ensure that the analysis represented the data. Later, through the discussions and reflections in the research group, all authors finally agreed on the core category, two categories, and five sub-categories.
Table 2. The fragment of the analysis process - Study III.

<table>
<thead>
<tr>
<th>Examples from the interviews</th>
<th>Codes</th>
<th>Sub-categories</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>There’s a little bit of fear I think, when something is more wrong than usual. Now something has broken.</td>
<td>Fear Worry Uncertainty Irritation Self-pity Doesn’t like to complain Denial</td>
<td>Thoughts and feelings about troubling situations</td>
<td>Normal daily life despite aggravating circumstances</td>
</tr>
<tr>
<td>Sometimes, it can kind of come back and then I feel my jaw joint pop. And can be painful. Yes, it is somewhat irritating.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slightly irritated at times that it clicks every time you chew.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, so I talk to my mom about it a lot and feel sorry for myself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have so much pain in the jaw and so on...but...one doesn’t like to complain. So...one only mentions it in passing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You live in denial a bit and hope that it will eventually pass of its own accord.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s simply a matter of accepting things as they are. Some people are born with blue eyes and some with brown...some are born with a sensitivity to pain and others are born without feeling as much pain. And now I happen to be one of those who feel pain easily. And there’s nothing to be done about it.</td>
<td>Living a normal life Ignoring the discomfort Acceptance Carry on working Normalization</td>
<td>Strive to maintain a normal daily life</td>
<td></td>
</tr>
<tr>
<td>The thing that affects me most is when I have a headache (...) but that doesn’t prevent me from doing anything. But, at the same time, it’s something I think about a great deal.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s not as if I’m home from work or that it affects my everyday life, but it (locking) can be uncomfortable.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s a common problem but one that is never spoken about... (...) I never felt that it was something strange either because I’m sure there must be others who have that kind of thing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I’m at a restaurant and I’m not satisfied with the meat (...) maybe not everyone complains that the meat was not good...but, to me, it’s like (...) I suffer from chewing this piece.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3. The fragment of the analysis process - Study IV.

<table>
<thead>
<tr>
<th>Examples from the interviews</th>
<th>Open codes</th>
<th>Selective codes</th>
<th>Sub-categories</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes it’s better not to have too high expectations</td>
<td>Patients’ wishes</td>
<td>Patient’s perspective of the issue</td>
<td>Correctly interpreting the patients’ needs and expectations</td>
<td>Living up to expectations of others on professional role</td>
</tr>
<tr>
<td>Important to understand patient’s needs</td>
<td>Patients’ needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not everyone wants the treatment</td>
<td>Expectations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>They are so stressed that they don’t have time to have the treatment</td>
<td>Patients’ ability to express feelings</td>
<td>The role of psychosocial factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Those who can afford it are more active and demand treatment</td>
<td>Demands</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If they are willing to pay that much</td>
<td>Patients’ financial situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well I can’t see pain ... am I understanding it right?</td>
<td>To listen and to understand</td>
<td>Identifying and understanding the symptom picture</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need to find clinical signs that confirm patient’s symptoms</td>
<td>Being certain about the symptoms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s not like it was at school when it comes to charging</td>
<td>Time restrictions</td>
<td>Focus on the financial situation in public dental care</td>
<td>Structural mechanisms within dental care as an organization</td>
<td></td>
</tr>
<tr>
<td>Check-up times only get shorter and shorter</td>
<td>Incomes and finances</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-supporting adult dental care</td>
<td>Differences between dental school and clinic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consult specialists if needed, the clinic arranges some meetings from time to time</td>
<td>Meeting with specialists</td>
<td>Management’s directives affect</td>
<td></td>
<td></td>
</tr>
<tr>
<td>You talk about team revenue during staff appraisals</td>
<td>Hour revenue</td>
<td>individual priorities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It was long time ago I had any courses, but it was in implants</td>
<td>Courses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly prosthetic treatment</td>
<td>Some treatments</td>
<td>Priorities in dental care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency patients and children are prioritized.</td>
<td>more frequent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s lack of staff here, we need to prioritize</td>
<td>Staff shortage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You need to be good in everything in inland</td>
<td>Location</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Results

Studies I and II

In total, 180,308 individuals (equal gender distribution, median age 29 years) were examined in 525,707 dental examinations at the PDHS in the Region of Västerbotten from 2010 to 2017. A median of three dental check-ups was registered during the study period (Table 4). The percentage of data coverage was higher than 88% every year except for 2010 when the 3Q/TMD was introduced and therefore covered shorter period of time.

Table 4. Demographical characteristics of the total sample in Studies I and II together with the number of examinations for each individual during 2010 – 2017 for the whole sample group (n=180,308).

<table>
<thead>
<tr>
<th>Sample (n)</th>
<th>180,308</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age [IQR]</td>
<td>29.0 [13.0]</td>
</tr>
<tr>
<td>Number of examinations (n (%))</td>
<td>38,026 (21.1)</td>
</tr>
<tr>
<td></td>
<td>35,794 (19.9)</td>
</tr>
<tr>
<td></td>
<td>42,724 (23.7)</td>
</tr>
<tr>
<td></td>
<td>38,518 (21.4)</td>
</tr>
<tr>
<td></td>
<td>18,921 (10.5)</td>
</tr>
<tr>
<td></td>
<td>5,165 (2.9)</td>
</tr>
<tr>
<td></td>
<td>1,041 (0.6)</td>
</tr>
<tr>
<td></td>
<td>119 (0.1)</td>
</tr>
</tbody>
</table>
Prevalence

TMD - orofacial pain and jaw catching/locking

Self-reported TMD (Q1/Q2/Q3) was most prevalent among adults in the 20 – 40 years age group (Figure 5A). This pattern was consistent over all studied years. The prevalence of self-reported orofacial pain was higher when compared to jaw catching/locking in the studied sample (Table 5). Furthermore, in contrast to jaw catching/locking, there was a significant increase in prevalence of orofacial pain over time (Figure 5B).

Figure 5. The estimated prevalence of TMD (CI 95%) in the project sample (Studies I and II): (A) as a function of age for individual years from 2010 to 2017; together with (B) the prevalence separately for Q1, Q2, and Q3 from 2010 to 2017.
Table 5. The one-year period prevalence of jaw catching/locking and orofacial pain with 95% confidence interval (CI) for the full study period for the whole study population. The proportion of screened individuals at regular dental check-ups for each year is given as a percentage of data coverage. The individuals screened as positive jaw catching/locking and orofacial pain are identified as cases.

<table>
<thead>
<tr>
<th>Year</th>
<th>Coverage (%)</th>
<th>n</th>
<th>Cases</th>
<th>Prevalence (95 % CI)</th>
<th>Cases</th>
<th>Prevalence (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>51.7</td>
<td>37,647</td>
<td>888</td>
<td>2.4 (2.1-2.7)</td>
<td>2,066</td>
<td>5.5 (5.3-5.7)</td>
</tr>
<tr>
<td>2011</td>
<td>88.8</td>
<td>68,563</td>
<td>1,293</td>
<td>1.9 (1.7-2.1)</td>
<td>3,275</td>
<td>4.8 (4.6-5.0)</td>
</tr>
<tr>
<td>2012</td>
<td>89.3</td>
<td>64,751</td>
<td>1,282</td>
<td>2.0 (1.8-2.2)</td>
<td>3,250</td>
<td>5.0 (4.8-5.2)</td>
</tr>
<tr>
<td>2013</td>
<td>90.3</td>
<td>66,181</td>
<td>1,312</td>
<td>2.0 (1.8-2.2)</td>
<td>3,287</td>
<td>5.0 (4.8-5.2)</td>
</tr>
<tr>
<td>2014</td>
<td>92.6</td>
<td>67,049</td>
<td>1,476</td>
<td>2.3 (2.0-2.5)</td>
<td>3,762</td>
<td>5.6 (5.4-5.8)</td>
</tr>
<tr>
<td>2015</td>
<td>93.9</td>
<td>76,826</td>
<td>1,670</td>
<td>2.2 (2.0-2.4)</td>
<td>4,496</td>
<td>5.9 (5.8-6.0)</td>
</tr>
<tr>
<td>2016</td>
<td>95.0</td>
<td>74,601</td>
<td>1,692</td>
<td>2.3 (2.1-2.5)</td>
<td>4,565</td>
<td>6.1 (6.0-6.2)</td>
</tr>
<tr>
<td>2017</td>
<td>95.0</td>
<td>70,089</td>
<td>1,598</td>
<td>2.3 (2.1-2.5)</td>
<td>4,558</td>
<td>6.5 (6.4-6.6)</td>
</tr>
</tbody>
</table>
Gender aspect - women versus men

In 2010, the prevalence of orofacial pain (Q1 and/or Q2) and jaw catching/locking (Q3), respectively, was significantly higher in women when compared to men (7.8% vs. 3.2%; OR 2.58, 95% CI 2.48-2.68 and 3.2% vs. 1.5%; OR 2.11; 95% CI 1.83-2.43). The prevalence of orofacial pain increased in both women and men over time, whereas the prevalence of jaw catching/locking remained similar over time in both women and men (Figure 6).

Figure 6. The prevalence of orofacial pain (Q1 and Q2) and jaw catching/locking separately (Q3) (CI 95%) in women and men 2010-2017.

Incidence

The annual incidence rate for self-reported orofacial pain (Q1 and/or Q2) was significantly higher when compared to jaw catching/locking (Q3). Both annual incidence of orofacial pain and jaw catching/locking were higher in women than men. Women were also at a higher risk than men for reporting TMD symptoms in consecutive dental examinations (Table 6).
Table 6. Incidence and risk of developing orofacial pain or jaw catching/locking.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Cases n (%)</th>
<th>Annual incidence (%)</th>
<th>Incidence Rate Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Incidence orofacial pain (n =135,800)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>6,594 (4.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>4,541 (6.8)</td>
<td>2.49</td>
<td>2.37 (2.25-2.50)</td>
</tr>
<tr>
<td>Men</td>
<td>2,053 (2.9)</td>
<td>1.22</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Incidence persistent orofacial pain (n=101,813)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1434 (1.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1012 (2.0)</td>
<td>0.70</td>
<td>2.56 (2.28-2.87)</td>
</tr>
<tr>
<td>Men</td>
<td>422 (0.8)</td>
<td>0.28</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Incidence jaw catching/locking (n =139,727)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2,543 (1.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>1,753 (2.5)</td>
<td>1.05</td>
<td>2.29 (2.11-2.49)</td>
</tr>
<tr>
<td>Men</td>
<td>790 (1.1)</td>
<td>0.46</td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Incidence persistent jaw catching/locking (n= 104,644)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1094 (1.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>757 (1.5)</td>
<td>0.50</td>
<td>2.32 (2.04-2.63)</td>
</tr>
<tr>
<td>Men</td>
<td>337 (0.6)</td>
<td>0.20</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Relationship between orofacial pain and jaw dysfunction

Overlap based on dental visits

In total, 29,261 (5.1%) dental examinations with reported orofacial pain (Q1 and/or Q2) or jaw catching/locking (Q3) from the study cohort were available for the descriptive relationship analysis. Pain in the absence of pain on function and in the absence of jaw catching/locking (Q1) was reported in 41.5% (n=12,146) of these dental examinations and pain only on jaw function (Q2) was reported in 7.8% (n=2,268). Jaw catching/locking in the absence of any pain (Q3) was reported in 22.0% (n=6,448) of dental examinations. Jaw catching/locking and orofacial pain together were reported in 16.3% (n=4,763) of dental examinations (Figure 7).

![Venn diagram showing relationships between Q1, Q2, and Q3](image-url)

*Figure 7. The relationship between self-reports of 3Q/TMD over 2010-2017.*
Onset based on individuals

In total, data from 6,594 individuals (4.9%) were available for descriptive onset analysis. The onset of exclusively orofacial pain or jaw catching/locking as an independent symptom during the study period was reported by 84.1%. The onset of jaw catching/locking as an independent symptom during the study period was reported by 19.2%. The onset of orofacial pain, followed by a later onset of jaw catching/locking, was reported by 1.3%, whereas onset of jaw catching/locking followed by a later onset of orofacial pain was reported by 1.2%. A concurrent onset of jaw catching/locking and orofacial pain was reported by 13.4% (Figure 8).

![Figure 8. Four different constellations of the onset of orofacial pain and jaw catching/locking.](image-url)
Studies III and IV

The findings from the qualitative studies were generated from the semi-structured interviews that included 16 participants (10 women and 6 men, aged 20-65 years) for the patient study (Study III) and 22 participants (15 women and 7 men) for the dentist study (Study IV). Descriptions of the participants in both studies are provided in Table 7.

Table 7. Characteristics of the participants in Studies III and IV.

<table>
<thead>
<tr>
<th>Geographical area of Västerbotten (Coast/Inland)</th>
<th>Type of practitioner (PDHS/PP)</th>
<th>Gender (men/women)</th>
<th>Median age (range) (years)</th>
<th>Median years as a dentist (range) (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dentists</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15/7</td>
<td>19/3</td>
<td>7/15</td>
<td>44.5 (25-64)</td>
<td>14.5 (1-40)</td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10/6</td>
<td>11/5</td>
<td>6/10</td>
<td>31.5 (20-65)</td>
<td>12/6*</td>
</tr>
</tbody>
</table>

*Two study participants were diagnosed with both pain and intra-articular disorders.

The semi-structured interviews covered the following topics: the role of dentistry when interviewing the dentists, the experiences of TMD treatment when interviewing the patients, and the decision-making for managing TMD when interviewing both the dentists and the patients. The qualitative analyses of the transcribed interviews resulted in the following theme: Seeking care when the situation becomes untenable, but dental care fails to meet all needs – from the patients’ interviews; and in the core category Combining own competence and others’ expectations in the desire to do the right thing – from the dentists’ interviews. The core category covers the process of decision-making in the management of TMD in dentistry and the theme covers the living experiences of TMD and
its management in a daily life. The main findings are summarized in the illustration below (Figure 9).

Figure 9. The core category and the theme together with the adjacent categories that emerged after data analysis from Study III (blue) and Study IV (green).

Process of decision-making from different points of view

The patients shared their thoughts and feelings about the TMD symptoms and reflected on the decision-making to seek treatment. The decision to seek professional advice was predominantly related to the severity of the symptoms and its impact on daily life. The participants talked about their own strategies to deal with the problems, partly by changing habits, partly by adapting to pain or dysfunction. Trying to solve the problem on your own programmed the mindset positively – to deal with the problems and try to solve them. The severity of the symptoms and inability to deal with them on their own guided the decision to seek professional advice. Nevertheless, fear, concern, and irritation due to the TMD symptoms affected individual’s cognition. However, individuals were striving to live as normal of a daily life as possible. Ignorance of disability and acceptance of the symptoms as a part of the daily life were present together with a wish to alleviate the symptoms of TMD.
Citations from the category **Normal daily life despite aggravating circumstances**:

“I have so much pain in the jaw and so on...but...one doesn’t like to complain. So...one only mentions it in passing.” (Participant 14, Study III)

“It’s simply a matter of accepting things as they are. Some people are born with blue eyes and some with brown... And now I happen to be one of those who feel pain easily. And there’s nothing to be done about it.” (Participant 13, Study III)

Citations from the category **Breaking point for seeking medical care depends on the manageability of discomfort**:

“It was very much avoidance behavior, trying to avoid it and I thought a great deal about what I ate, that it should be a lot of liquid foods.” (Participant 1, Study III)

“Well, it was because it became unsustainable. It hurt so much just to eat normal foods. I felt cramps in the whole jaw when I tried to eat some food that was not even difficult to chew...just normal food. And it was like this every day, so it became unsustainable.” (Participant 7, Study III)

From the dentists’ clinical points of view, the decision-making process for managing patients with TMD was based on professional knowledge and clinical experience, but biased by both internal and external factors. The participants illustrated the decision-making for TMD as an especially complex process in their clinical decision-making. Structural mechanisms and correct evaluation of the patients’ symptoms were emphasized in the process towards the final clinical decision. Thus, dentists were aware of their legal responsibilities and striving after the correct interpretation of the clinical situation, but the time restrictions, hourly revenue, and staff shortages complicated the decision-making process.
Citations from the category Living up to expectations of others on a professional role:

"You prioritize fillings, perio, prosthetics, and oral hygiene a bit more, so you [TMD] do not end up so high on the list. But I relate it to staff shortage. If we go to the bottom...We have all the same education, so you must have the same available information. So, I think that it is because of the staff shortage.” (Participant 6, Study IV)

“Many times it is hard for them to describe (the symptoms) and for me to understand...which level it is (...) which I cannot see, it is only based on the interview (...) To meet each other on the same level.” (Participant 4, Study IV)

Two perspectives on the role of dentistry in the management of TMD

The patients shared their experiences from their dental visits regarding TMD. The existing resources, such as one’s own financial asset, initiative, access to healthcare and dental care in the living area played a substantial role in the narratives. The experiences of the contact with the dental care professionals showed discrepancy between the expectations and the outcomes of the TMD management. On the one hand, experiences of distrust, lack of acknowledgement, and not being seen by the dentist were identified. On the other hand, a wish to be involved in planning the treatment, wish to be heard and taken seriously, and making active choices came up as a desirable form of the contact with the dentist. Furthermore, other healthcare professionals besides dentists were involved in the management of the jaw-related problems since the participants had read or heard, or had already previous experiences of alternative treatments for TMD.
Citations from the category **Difficulties to get the right treatment:**

“I’ve been to a naprapath... That’s what they’re called, isn’t it? He usually massages my jaw. And he says that I must chew more on this side (points).” (Participant 3, Study III)

“And dentists aren’t cheap. It is expensive (...) And especially if you’re on sick leave, with a really, really low income, it makes an enormous difference.” (Participant 14, Study III)

“I assume that they didn’t have the competence. And then... or that they don’t...As we have spoken specifically about bite guards, so perhaps they don’t manufacture them there (...) The clinic I go to is very small.” (Participant 6, Study III)

Citations from the category **Expectations of dental care providers normally not met:**

“I think that it would have been nice with more acknowledgement. Just that - oh, I understand that it’s hard. Just that kind of thing helps a little bit because then it feels more like you are taken seriously.” (Participant 9, Study III)

“So, during several medical examinations I described this pain in the jaw joints and all that it entails, it’s so terribly painful that it’s an obstacle to doing my work. But, as far as I can tell, they simply refuse to believe it. I was like... it was quite new probably... It seems like this is a welfare issue? A problem of the modern society.” (Participant 16, Study III)

"It wasn't two people communicating behind my back or whatever... I understand that dental language is not necessarily comprehensible to many people but... this time it was completely silent the whole time, so I had to ask about it myself. It was very much on my own terms. Of course, there was a lot she wanted to explain to me, and that's great... but it wasn't like she was doing her own thing and I wasn't there.” (Participant 1, Study III)
The dentists’ attitudes towards the role of dentistry, regarding management of the patients with TMD, were mixed and the individual interest was of importance, although the continuous professional development was appreciated. Individual interest in TMD facilitated the management of patients with TMD and the positive feedback was encouraging. Individual interest in a particular dental area was also related to professional competence in that particular area. In other words, the clinical experience and knowledge of the area made one feel competent and confident, which leads to a greater interest in that particular dental area. The generalizations regarding the typical TMD complaints and management strategies encapsulated the management of patients with TMD as challenging in general, thus, making the dentist feel uncomfortable when dealing with TMD. Generalizations included TMD pain being something that could not be seen (as compared to dental caries), TMD conditions being complex, TMD being usually accompanied by comorbidities.

Citations from the category **Being comfortable with using own expertise:**

“It seems that the treatment that patients receive is dependent on the dentist they meet. I believe I have met several patients who told me that they had brought it up previously, but no one has…or it was neglected. And now they bring it up again and receive a treatment and then they wonder why nobody did anything before.” (Participant 7, Study IV)

“Of course, we need knowledge, I do not know when I had any courses so I use my old experience (...) so I am not updated in the new knowledge… But I try to do as good as I can.” (Participant 9, Study IV).

Taken together, the patient’s decision-making process starts before the clinical decision-making is of relevance. When the symptoms become the complaints, and when it is not possible anymore to deal with it, the decision to seek professional help (dental or non-dental) arises. However,
the process is not straightforward due to some barriers. As identified by the patients in our study, care availability, financial situation, and previous experiences affected the individual decision-making. The dentist’s decision-making also starts before the actual meeting with the patient who suffers from TMD. In the light of professional knowledge, continuous dental education, and clinical experience, the dentist is prepared to make a clinical decision when needed. In the actual situation, when having a patient with TMD in the dental chair, biases in terms of interpretation of the symptoms, patient’s expectations, time restrictions, staff shortage, and individual interest affect the decision-making. The structural barriers in the organization of PDHS were a common element highlighted in both the patients’ and the dentists’ interviews (Figure 10).

Figure 10. Illustration of the patient - dental practitioner interaction regarding the decision-making for- and experiences of the TMD and its management.
Discussion

The findings of this thesis demonstrated higher incidence, prevalence and persistence of TMD in women compared to men. Over time, the prevalence of orofacial pain increased, whereas the prevalence of jaw dysfunction remained similar. The onset of orofacial pain or jaw catching/locking was most frequently independent and exclusive, i.e. without the other symptom. The findings of this thesis also demonstrated a discrepancy between the care that the dentists would like to provide, and the patients would like to receive, in contrast to the daily challenges these both groups faced in the management of TMD.

Longitudinal perspective of TMD

Prevalence and incidence of orofacial pain and jaw dysfunction

An increasing number of musculoskeletal illnesses (Wiitavaara et al. 2017) and a growing burden of mental health disorders (The Public Health Authority 2022; World Health Organization 2012) have been observed worldwide. In Study I, we observed the increasing prevalence of orofacial pain in a general population over the study period. Orofacial pain is known to be closely related to comorbidities (Ohrbach et al. 2011; Sanders et al. 2013), and mental health disorders have been identified to contribute to both incidence and persistence (Fillingim et al. 2013; Velly and Fricton 2011) of orofacial pain. The increasing prevalence of general health disorders, including orofacial pain, indicates the global health impairment in the population. In Study II, the prevalence of jaw catching/locking remained similar over the study period. Intra-articular conditions like crepitation and locking in the TMJ were previously shown to have a steady course over time (Wänman 2005). Longitudinal studies that used diagnostic imaging showed longitudinal stability of intra-articular conditions (Salé et al. 2013; Schiffman et al. 2017). The radiographically confirmed stability of intra-articular conditions, together
with the knowledge of prognosis, are arguments that are in line with our findings. To sum up, according to the previous findings and to the findings from this project, the prevalence for orofacial pain and joint-related jaw dysfunction (including jaw catching/locking) differs regarding the longitudinal development that may be partly related to multifactorial etiology (Suvinen et al. 2005) and differences in pathophysiological pathways. However, the conditions share some similarities as well. Firstly, higher prevalence in women than men nearly throughout the whole age span is noticeable in both orofacial pain and in jaw catching/locking. This female preponderance is consistent over time and will be discussed separately in the forthcoming paragraph with regard to gender differences. Secondly, similar age groups have the highest prevalence of both orofacial pain and in jaw catching/locking. Considering these age groups in a wider perspective, health development is a non-linear process and is related to biological, psychological, and social factors as well as to different phases in an individual’s life (Halfon et al. 2014). Different events during the lifespan can affect health in various ways; for example, obesogenic environment in late adolescence and job insecurity in late adulthood affect health development negatively (Halfon et al. 2014). Lastly, orofacial pain and jaw catching/locking showed a co-existence in approximately 15% of the cases in our sample. The presence of multiple diagnoses in patients with TMD was previously discussed in the context of care-seeking and referrals to the specialized clinics (Pimenta e Silva Machado et al. 2009), which emphasizes that patients with overlapping symptoms are usually managed outside the primary dental care.

In the literature, the annual incidence of TMD ranges from 2.0% to 4.0% (LeResche et al. 2007; Nilsson et al. 2007; Sanders et al. 2013) and the gender differences are debated (Bair et al. 2013; Nilsson et al. 2007; Slade et al. 2013). In contrast to previous findings on a similar incidence of TMD in women and men (Slade et al. 2013), we found that the TMD incidence is higher in women than in men (Studies I and II). Women are at higher risk to develop both the first onset TMD and, more importantly, persistent TMD symptoms. Persistent TMD symptoms have been reported to occur in almost half of the cases (Dworkin 2011; 2013; Rammelsberg et al. 2003; Slade et al. 2013). The transition has been explored with regard to pain intensity, comorbidities, and psychosocial factors. Here, genetic risk factors and environmental factors were identified to have a substantial role (Ferrando et al. 2004; Meloto et al. 2019). This transition, in terms of
joint-related jaw dysfunction, has also been explored, and it was suggested that the clinical status of the intra-articular changes may not always be of relevance for the patient’s perception of the symptoms (Chantaracherd et al. 2015).

**Independent onset of orofacial pain and jaw dysfunction**

Considering the differences between the longitudinal prevalence of orofacial pain and jaw catching/locking, makes it interesting to realize how these two conditions develop in relation to each other; particularly, because reports on the relationship between orofacial pain and joint-related jaw dysfunction are conflicting (Chantaracherd et al. 2015; Emshoff and Rudisch 2003). The findings of this thesis demonstrated that most frequently the onset of orofacial pain and jaw catching/locking was independent and exclusive, which reinforces the pathophysiological differences between these two conditions. Pathophysiological mechanisms have been explored previously regarding the overlap of the painful conditions. It is known that chronic overlapping pain conditions share several pathophysiological mechanisms such as altered pain perception and processing, neurocognitive and behavioral functions, central arousal circuits, and sleep problems (Aaron et al. 2000; Gatchel 2004; Slade et al. 2016). However, it is also known that the intensity of musculoskeletal pains may be mutually additive, while the intensity of other pains (headache or irritable bowel syndrome) may be processed separately (Ohrbach et al. 2020).

The overlap of orofacial pain and joint-related jaw dysfunction is commonly observed at the specialist clinics (Lövgren et al. 2018b). The potential reason may be related to the complexity of the cases referred to specialist clinics. However, on a population level, we demonstrated that the overlap is substantially rarer than the independent onsets. The theories of heightened symptom awareness and hypervigilance consider that mechanical factors, including jaw locking, are reported more commonly by both individuals with orofacial pain and those with widespread pain (Macfarlane et al. 2001). In addition, higher levels of kinesiophobia and catastrophizing are reported by individuals with painful and non-painful TMD (Häggman-Henrikson et al. 2022). Such
findings consider the overlap between orofacial pain and jaw catching/locking as more of a symptom due to the increased awareness than as a shared pathophysiological path.

Gender differences

Gender differences in TMD have been an interesting research topic for a long time. It is hardly surprising since the reasons for higher vulnerability in women when compared to men have not been fully elucidated. Furthermore, women being at a higher risk to develop TMD has also been debated (Bair et al. 2013; Slade et al. 2013). However, quite a few studies have observed gender differences already in adolescence (Köhler et al. 2009; Nilsson et al. 2007) and consolidated the hypotheses of the biological factors involved in the process.

In the light of the biological components in TMD, according to the biopsychosocial model, it would be reasonable to discuss hormonal theories as a possible contributing factor to the gender differences. Some studies have shown that a cumulative amount of estrogen in blood predisposed higher odds for TMD (LeResche et al. 1997) and that testosterone predisposed a lower prevalence of TMD (Fischer et al. 2007). Gender differences to some extent could also be related to co-morbidities (Sanders et al. 2013) with TMD being a part of a general health impairment in the population. Regarding the psychological component, stress and anxiety are related to the development of TMD (Fillingim et al. 2013), and mental health disorders are considerably higher in women when compared to men (Otten et al. 2021). Social and behavioral components is another aspect of gender differences (Westergaard et al. 2019), e.g. women are more aware of their own health issues and are more prone to seek healthcare than men (Kuttila et al. 1997; Thompson et al. 2016).
Qualitative perspective of TMD

Transition from patient-centered care to person-centered care

Patient-centered care is a concept encouraged by EBM to implement in clinical settings. In our project, patient-centered care was a natural way of thinking as identified by both dentists and patients. The dentists embraced their task to apply their professional expertise in order to do ‘the right thing’. The right thing was not only a clinical application of professional knowledge but also a patient-centered care. Patients explained that it felt right to have an active role in planning the treatment and being seen by a dentist. However, TMD management seemed to be challenging and suboptimal.

Lately, the concept of patient-centered care has evolved into a concept of person-centered care (Håkansson Eklund et al. 2019). Initially, the person-centered care was explored in psychiatric and geriatric healthcare settings (Kogan et al. 2016). Philosophically, this concept focuses on ethical aspects with regard to distinguish humans from everything else, and characteristics of a human being in terms of free will, communication, capability, and self-consciousness (Ekman et al. 2011). The purpose of the person-centered care is to “see the person behind the illness”. The main difference from the traditionally used patient-centered care is that person-centered care shifts the perspective of the clinician; instead of seeing a patient as an object suffering from a disease, the patient is seen as a human being with an active role in the decision-making (Ekman et al. 2011; Holmstrom and Roing 2010). According to an overview study (Håkansson Eklund et al. 2019), person-centered and patient-centered care both involve (1) empathy, (2) respect, (3) engagement, (4) relationship, (5) communication, (6) shared decision-making, (7) holistic focus, (8) individualized focus, and (9) coordinated care. The same words are used to describe both person-centered and patient-centered care but they seem to carry different meanings since the goal of person-centered care is a meaningful life, whereas the goal of patient-centered care is a functional life (Håkansson Eklund et al. 2019). In other words, person-centered care places a disease in a perspective of a daily life of an
individual including psychosocial aspects. In accordance with the findings from our studies (Studies III and IV), it would be reasonable to suggest that the shift from patient-centered care to person-centered care in managing TMD could be an alternative strategy for improvement of the current challenges.

Shared Decision-Making

From the analysis of our data, the concept of using Shared Decision-Making (SDM) in dentistry emerged. SDM is based on continuous interaction between the patient and the caregiver, resulting in a mutual decision; moreover, SDM is a part in a patient/person-centered care (Barry and Edgman-Levitan 2012; Elwyn et al. 2012). The similarities and differences between EBM and SDM have been described together with the discussions of whether SDM is a part of EBM (Elwyn et al. 2012). Eventually, “EBM cannot exist without SDM” (Hoffmann et al. 2014) as the importance of mutual management of the health issues preponderates. This engages not only involving the patient into the process of decision-making towards the specific management method, but also involves the patient into continuous awareness regarding their own health. Particularly in the management of TMD, it is of relevance since the management is often depending on cooperation, e.g. jaw exercises at home or use of a splint. To succeed in this process, it is important that the patient receives all the information and guidance. However, it is challenging to get a positive effect without cooperation from the patient. Similar challenges have been observed in physiotherapy where SDM was suggested to be an integral part of the clinical practice (Hoffmann et al. 2020). To improve the process of such integration, collaboration between researchers, clinicians, and policy makers was suggested (Topp et al. 2018).

Decision-making for TMD in different settings

In the management of TMD, we explored the decision-making process in two entities – patients and dentists. Recounting our findings from this thesis, we also observe a hint of decision-making on different levels, from
the individual to organizational factors. We identified the role of organizational factors in the process of decision-making, but we did not investigate the decision-making process on the organizational level and in the different healthcare facilities. Traditionally, TMD is managed by dentists since this is the group of professionals having the formal education and expertise for TMD management.

Dental care settings

In a dental setting, patients with TMD may receive some different TMD management approaches depending on the dentist they meet. As was demonstrated in our study (Study IV), the care applied was partly related to the individual interest of the dentist. However, despite the individual interest, there are differences in TMD management that depend on the type of dentist that the patient meets, i.e. a general practice dentist, a specialist in TMD, or another specialist dentist, e.g. oral surgeon (Greene and Bertagna 2019). Furthermore, even if there are guidelines for diagnostics and treatment of TMD, some dentists adhere to the mechanical model for TMD management, whereas others follow the biopsychosocial model (Lindfors et al. 2016; Reid and Greene 2013). Here, a collaboration between the dentists would probably give the most appreciable results for the patient.

Healthcare settings

Even though traditionally TMD is managed by dentists, dental education and management of TMD differ worldwide; it is one of the reasons why in some contexts TMD is managed by non-dental healthcare professionals. Another reason for TMD being managed by healthcare professionals other than dentists is that patients with TMD can suffer from other health problems, usually pain (Costa et al. 2017). Thus, such treatments focus primarily on other health issues that may be related to TMD. As was also reported by participants in our study (Study III), patients were eager to solve the problems on their own, or sometimes to seek help from different healthcare professionals like physiotherapists, acupuncturists, or chiropractors. A recent study has performed a survey on knowledge and competence among non-dental healthcare professionals treating TMD
(Greene and Bertagna 2019). The findings showed that there was lack of professional expertise for diagnostics and treatment of TMD. More importantly, the authors concluded that there was a risk for patients to receive an inappropriate treatment since most of these non-dental healthcare providers did not have any formal education on TMD (Greene and Bertagna 2019).

Also in Sweden, patients with TMD meet different healthcare professionals. Even if the dentists have the formal education in managing TMD, it is still a challenging task, as described in our own study (Study IV) and by other researchers (Al-Baghdadi et al. 2019; Durham et al. 2007). TMD management shows a positive effect in most cases, however, some patients develop chronic symptoms or do not respond to the provided treatments. It is also known that in such cases, especially if irreversible therapies have been used, the negative outcomes are likely to be even worse (De Leeuw and Klasser 2018). Therefore, it is not surprising that patients with TMD sometimes seek help from alternative healthcare providers. In this respect, the correct clinical assessment and prognosis at a dental setting are of importance (Studies I and II). If the patient received adequate information (Study III) and the dentist met the patient “on the same level”, as expressed by one of our participants (Study IV), it would probably create a better balance of the TMD management.
Clinical implications

The findings from this thesis demonstrated that the prevalence of orofacial pain increased over time in both women and men. The increasing prevalence indicates a probable increase in future treatment need. This is an important epidemiological aspect in planning the clinical capacity, especially when having a frequent staff shortage. Having such an undertreatment of TMD together with an increasing prevalence of TMD may indicate future challenges in clinics.

Furthermore, the most frequent independent and exclusive, i.e. without the other symptoms, onset of orofacial pain or jaw catching/locking reinforces differences in the pathophysiology of these two conditions. This finding gives clinical value in terms of clinical assessment and prognosis for the condition.

The findings from this thesis demonstrated a discrepancy between the desirable TMD management and the challenges faced on a daily basis by both patients and dentists. These challenges were closely related to the structural organization of the PDHS, e.g. staff shortage, time restrictions and costs for the dental treatment. The findings point to the potential for improvement at the organizational level.
Methodological considerations

Studies I and II

The studies on orofacial pain and jaw catching/locking in this thesis are unique in the research field of TMD. The uniqueness lies in the large population-based sample from the general population that was followed for the period of eight years. This large data set was available through the local dental register in the Region of Västerbotten. In general, registry-based studies allow longitudinal evaluation of data with only a small risk for selection bias. In our project, we were able to track the development of TMD together with a time-to-event analysis. Regarding study design, just as the other registry-based studies, our studies also faced some limitations. Registry-studies may face a lack of data verification. In our studies, data were collected using the screening instrument 3Q/TMD as a part of a routine dental check-up. The 3Q/TMD identifies patients who would benefit from TMD examination (Lövgren et al. 2016b). While the screening questions for orofacial pain showed high validity and reliability, the screening question for jaw catching/locking was assessed with fair to moderate validity with 0.45 sensitivity and 0.86 specificity (Lövgren et al. 2016b). The low sensitivity made the Q3 inferior to the Q1 and Q2 in prognostic ability according to the DC/TMD. However, an affirmative answer to Q3 was positively associated with patients’ reported treatment need (Fjellman-Wiklund et al. 2019). So, even if a clinical diagnosis according to DC/TMD was not always present, the symptoms and subjective treatment need were most probably present. Furthermore, regarding diagnostics of the joint-related jaw dysfunction, clinical examination also has difficulties in its diagnostic accuracy (Schiffman et al. 2014). Thus, the use of the validated screening tool 3Q/TMD in the present studies presented the best available method for cost-effective research of jaw dysfunction in a large population sample.

In continued discussion of the 3Q/TMD, age-related difficulties to understand and to answer the screening questions need to be elaborated. Since the study sample for Studies I and II covers almost the whole lifespan (5-104 years), it is reasonable to speculate on the reports from the youngest and the oldest participants (or even participants with cognitive
To the best of our knowledge, age-related barriers are more common for advanced questions than for those with dichotomous answers (Knauper et al. 2016); so the risk was reduced in the present studies by the use of dichotomous screening questions. Furthermore, the youngest and oldest patients were usually accompanied by parents or guardians who could assist with interpretation and answering of questions. Another aspect of this consideration takes us back to the beginning of the introduction of the screening questions to the Swedish dental care. The screening questions on orofacial pain were primarily introduced and validated on adolescents (Nilsson et al. 2006), which strengthens their sufficiency for use at different ages. The National Board for Health and Welfare highlighted the need for screening at the dental healthcare services since dental professionals meet most of the population on a regular basis (National Board Health and Welfare 2021). Screening enables systematic work and creates conditions for risk assessment. By that, adequate care can be provided that focuses on causes to the problem and not only treatment of the symptoms.

In addition to age-related difficulties, one could argue that our findings are based on subjective data – patients’ own reports of TMD. Firstly, it would be certainly challenging to collect such a large amount of data using clinical examinations or diagnostic imaging for joint-related jaw dysfunction. The challenges cover not only the practical performance, but also the ethical issues. Secondly, according to The International Association for the Study of Pain (IASP), pain is “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”. In other words, it is a subjective outcome, so the self-report from the validated instrument is an adequate method for data collection and interpretation. Lastly, self-reported jaw dysfunction, e.g. jaw catching/locking is related to perceived treatment need (Fjellman-Wiklund et al. 2019) indicating the presence of the symptoms.

The county of Västerbotten consists of nearly 270,000 inhabitants, of which ~180,000 (70%) have routine, regular dental examinations, and more than half (54%) of these are performed at the PDHS (National Board for Health and Welfare 2018). In this setting, we found a coverage of more than half of the population in Västerbotten, which is well in line with acceptable coverage for surveys in general of 50-60% (Nulty 2008). The
frequency of routine dental examinations in Sweden varies from approximately once per year to once every two or three years and depends not only on a patient’s own initiative but also on the dental health of the patient as determined by the dentist. In the present studies, the median number per individual was three dental examinations over the eight-year period. Extrapolation of the findings outside the study’s follow-up period should be done with caution but collectively the results should be generalizable for comparable settings.

Studies III and IV

Qualitative Content Analysis (QCA) and the Grounded Theory (GT) by Charmaz were the methods employed to explore the phenomena of TMD management in Swedish dental care. The GT is useful when trying to conceptualize a process, in this project – the process of decision-making when managing patients with TMD. The QCA is useful when aiming to give a voice to the participants in exploring experiences and perceptions. Combining these methods in the present project enabled a better understanding of the decision-making process for the management of patients with TMD together with the identification of the living experiences of TMD. In order to enhance trustworthiness of the qualitative studies, four strategies were used – credibility, confirmability, dependability, and transferability (Dahlgren et al. 2007) (Table 8).
Credibility – have we explored what we aimed to explore?

The authors’ preconceptions varied about the decision-making process for the TMD management depending on different European contexts and the diverse expertise, i.e. general dentistry, specialist dental care, TMD, orofacial pain, physiotherapy, epidemiology, and qualitative methods. However, the research group stayed open-minded when conducting the qualitative studies and the preconceptions became rather a strength of having knowledge and skills for the research area than a limitation of holding back from a generation of a new knowledge. Since both authors who conducted the interviews were clinically active dental practitioners in the Region of Västerbotten at the time of the project, this gave an insider perspective that facilitated recruitment and interviewing. However, participants in the dentist study (Study IV) may have censored the information they were willing to share with a colleague. Therefore, strategies used to counteract such censoring were: (1) the recognition of these dual roles ahead of the interviews, and (2) ensuring participants’ privacy and confidentiality in the presentation of data. Credibility was also enhanced by peer-debriefing and triangulation (Lincoln and Guba 1985). The preliminary findings of both studies were also presented at dental conferences, which allowed discussions with researchers not involved in the project. A member check was done with two participants in Study IV.
In order to stay closer to the text, the analysis process was performed in Swedish since all the interviews were conducted in Swedish. The translation into English was performed only after reaching a mutual agreement on findings.

Transferability – how applicable are our findings to other contexts?

Analytical generalization was enhanced by purposive samplings and also until theoretical saturation in Study IV (Saunders et al. 2018). The participants selected were thought to be able to contribute by fulfilling the aims of the studies. Naturalistic generalization was another method employed in order to allow the reader to judge whether the findings are applicable to other settings. We believe that our findings should be considered in other contexts to assure transferability, but we regard the findings representative for general practice dentistry in Sweden and in comparable countries.

Dependability – would the findings be the same if the study was replicated in the same setting with the same participants?

The whole research process in both qualitative studies (Studies III and IV) was considered to be reasonably consistent regarding both data collection and the analysis process, i.e. the interview guides were pretested, interviewers were calibrated, and researchers were also calibrated with a good agreement both before the interviewing and the data analysis process. However, it is possible that some interviews did not follow the standard manner, but we believe that all the topics were still sufficiently covered in all interviews. An emergent design was used in data collection together with data analysis and coding in parallel, which enabled the researchers also to be reflective in the research process in Study IV.

Confirmability – what impact did the personal interests and biases have on the findings?

The method of “bracketing” was used in order to stay neutral to the data and findings – no exclusion of the findings nor relation to the existing theories were performed until the data analysis was finalized.
Furthermore, the quotations, notes and memos were used to improve the confirmability of the findings. However, in the study IV, subjectivity was a part of the research process in line with the constructivist GT – that one cannot escape the prior knowledge. In order to counteract this, strategies of detailed process description and reflexivity were taken.
Future directions

The necessity of brief, yet reliable and valid, screening and diagnostic instruments for TMD have been highlighted, and the use of such instruments has been encouraged (Lobbezoo et al. 2022). 3Q/TMD is one of them, but establishment of the reliability of Q3 could provide an improved structure of the question capable to capture pure joint-related jaw dysfunction.

The concept of SDM in the management of TMD was observed through the qualitative lens of this project. SDM being a clinical form of EBM, emphasizes further investigation of how this model is applied and would be advantageous not only in the management of TMD but also in other dental fields.

Structural organization of a workplace should identify rules and regulations, and facilitate employees’ professional authority (Hagbaghery et al. 2004). However, challenges related to structural organization are evident in dental care provision and consumption. Therefore, the perspective of the leaders and managers at the dental clinics would be of interest to explore.
Main findings

- Prevalence and incidence of orofacial pain and jaw catching/locking are higher in women than men, and such proportion is stable over time.

- There is increasing prevalence of orofacial pain over time.

- There is no significant change in prevalence of jaw catching/locking over time.

- The onset of orofacial pain or jaw catching/locking is most commonly independent and exclusive, i.e. without the other symptom.

- There exists patients’ perception of an active coping with their TMD symptoms.

- Patients’ decision to seek help was based on the severity of the symptoms and their impact on daily living.

- It is important to be taken seriously by the dentist.

- There are challenges in accessing dental care for TMD symptoms.

- Dentists’ professional self-confidence and professional competence affect decision-making for management of patients with TMD.

- Structural organization of PDHS complicates both the access to the right care and the actual care delivery for patients with TMD.
Conclusions

- The increasing prevalence of orofacial pain may indicate an increase in future treatment-need.

- Gender differences exist in both orofacial pain and jaw catching/locking.

- The most common independent and exclusive onset of orofacial pain or jaw catching/locking reinforces that these two conditions differ in pathophysiology.

- Patients strive to deal with the symptoms and to have a normal life emphasizes efficient attitudes towards conquering TMD.

- Patients’ positive experiences of being involved in the decision-making to manage TMD accentuates the benefit of using SDM in care delivery.

- Postgraduate training may improve dentists’ professional self-confidence, while optimal work conditions may enable a successful application of the professional expertise.

- Scrutinizing the current structural organization of the PDHS is warranted for improved care access and care delivery for the patients with TMD.
Thesis at a glance

Orofacial pain and jaw catching/locking

Combining own competence and others’ expectations in the desire to do the right thing

Time
Expectations
Support

Symptoms
Fear
Expectations

Available
dental care
Previous
experiences
Finances

3Q
Previous
knowledge
Experience

Seeking care when the situation becomes untenable, but dental care fails to meet all needs

Clinical implications

Increase in treatment-need

Gender differences

Differences in pathophysiology

Increasing prevalence

Women at higher risk

Independent and exclusive onset

Increasing prevalence

Gender differences

Differences in pathophysiology

Orofacial pain and jaw catching/locking
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