Temporomandibular disorders among Sami women
Perspectives based on an epidemiological survey with mixed methods

Christina Storm Mienna
To Alexander

“Just as the mountain spring flows, so is life. It is like a river we cannot stop, but can only try to accept.”

(Quotation from a 48-year-old woman)

"Precis som jokken rinner, så är vårt liv. Det är liksom ett flöde som vi inte kan stoppa, utan får försöka acceptera.”

(Citat från kvinna 48 år)
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Abstract

Introduction The aim of the research project was to examine prevalence, co-morbidity, and impact on daily life of pain and dysfunction in the jaw–face, head, and neck–shoulder regions among adult Sami women in northern Sweden. The aim of the qualitative part of the study was to explore, thoughts, experiences, and beliefs regarding temporomandibular disorders (TMD) among Sami women with and without TMD, to gain insights into their health care experiences.

Methods The research project used a mixed methods approach including questionnaire analysis, a case–control study, and thematic interviews. The study population (Papers I and III) included 487 women living in the Arctic region of northern Sweden and enrolled in the register of the Swedish Sami Parliament or registered as reindeer owners or reindeer herders in the Swedish Board of Agriculture. Two years after the questionnaire study, 22 women (cases) with longstanding, intense, and frequent symptoms indicative of TMD, together with 46 age-matched women (controls) without any symptoms in the jaw–face region, underwent a clinical examination of the function of the temporomandibular joint, jaw- and neck muscles, mandibular mobility, and dental occlusion. The examiner was blind to the women’s affiliation (Paper II). Thematic interviews with a strategic subsample of 17 Sami women (Paper IV) were thereafter conducted and analyzed with a grounded theory approach.

Results The prevalence of frequent symptoms indicative of TMD was 17%, of headaches 19%, and of neck–shoulder pain (NSP) 30%. Seventeen percent reported that their TMD affected daily life. Duration of jaw pain, troublesome impaired jaw opening, and neck pain, together with a low education level, affected the statement of whether TMD influenced daily life or not. Factors related to pain had the greatest influence when these Sami women rated the related impairment. There was a statistically significant relationship between TMD, frequent headaches, and frequent NSP (P < 0.0001). Longstanding, intense, and frequent symptoms indicative of TMD remained essentially unchanged over the two-year follow-up period. Cases reported impaired general health and awareness of clenching teeth significantly more frequently than did controls. Variations in dental occlusion did not distinguish cases from controls. In the qualitative part of the project the core category, “Grin(d) and bear it,” summarizes the participants’ various ways and stages of processing and handling the interacting categories: (1) triggers, (2) strains, (3) distrust, and (4) reconciliation with pain and/or difficulties in life. Perpetuating factors were
described as mental–physical strain and stress, and also a tooth clenching behavior. Women without TMD expressed factors that helped them to handle strains, reconcile, and stay healthy. They relied on helpful social support.

**Conclusion** Disabling TMD, headaches, and NSP are common in Sami women. Women with TMD commonly expressed that tooth clenching was a familiar habit related to strains in life; they described an impaired general state of health and distrust in the care providers’ competence and ability to manage their problems. Women without TMD expressed confidence in their self-efficacy and were generally less concerned with strains in their lives. Rehabilitation strategies aiming at empowerment and improved self-efficacy may be a successful approach in women with disabling TMD.

**Keywords:** epidemiology, gender, headache, indigenous, pain, qualitative, quality of life, temporomandibular disorders
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>activities of daily living</td>
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<tr>
<td>Ai</td>
<td>anamnestic dysfunction index</td>
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<td>BMI</td>
<td>body mass index</td>
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<tr>
<td>CI</td>
<td>confidence interval</td>
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<td>Di</td>
<td>clinical dysfunction index</td>
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<tr>
<td>GT</td>
<td>grounded theory</td>
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<tr>
<td>NRS</td>
<td>11-point numerical rating scale</td>
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<td>NSP</td>
<td>neck–shoulder pain</td>
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<tr>
<td>OHRQoL</td>
<td>oral health-related quality of life</td>
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<td>OR</td>
<td>odds ratio</td>
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<tr>
<td>RDC/TMD</td>
<td>Research Diagnostic Criteria for Temporomandibular Disorders</td>
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<tr>
<td>SD</td>
<td>standard deviation</td>
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<td>TMD</td>
<td>temporomandibular disorders</td>
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<td>TMJ</td>
<td>temporomandibular joint</td>
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Frekvent (minst en gång i veckan) återkommande smärtor och funktionsstörningar i käksystemet rapporterades av 17% av deltagarna i enkätstudien, frekvent återkommande huvudvärk av 19% och smärtor från nacke/skuldror av 30%. Sjutton procent av samtliga kvinnor angav att symtomen i käkarna påverkade deras dagliga liv negativt, och många av kvinnorna hade symtom från samtliga undersökta områden, som tecken på en samsjuklighet för tillstånden. Smärta från käkar hade störst betydelse när kvinnorna skattade hur symtom från käkarna påverkade deras dagliga aktiviteter, även nedsatt gapförmåga, smärta i nackregionen och låg utbildningsnivå av betydelse.

Alla kvinnor med långvarig, intensiv och frekvent smärtor och funktionsstörning i käksystemet erbjöds en klinisk undersökning 2 år efter enkätstudien; 22 TMD kvinnor (fall) och 46 åldersmatchade kvinnor (kontroller) utan några symtom från käkarna deltog. Undersökningsen var blindad dvs. visste inte vilka som var fall eller kontroller. Den kliniska undersökningen omfattade käkled, käkmuskulatur, käkrörlighet och bettförhållanden. Fall och kontroller hade likartade bettförhållanden. Fallen
hade högre body mass index (BMI) än kontrollerna. Kvinnorna inom fallgruppen rapporterade sämre allmän hälsa och högre medvetenhet om tandpressningsovanor än kontrollerna.


Sammanfattningsvis visar avhandlingen att smärta och funktionsstörningar i käksystemet, huvudvärk och smärta från nacke/skuldror är vanligt förekommande bland samiska kvinnor. Medvetenhet om tandpressning eller att hålla ihop käkarna förknippades med belastningar/spännningar i livet, nedsatt allmän hälsa och med symtom från käkarna. De som intervjuades och hade symtom ifrån käkarna uttryckte misstro mot vårdgivares kompetens och möjligheter att behandla deras problem i käkarna. De kvinnor som inte hade symtom uttryckte stark tilltro till sin egen förmåga att klara av svårigheter och var i allmänhet mindre oroliga för påfrestningar i livet.

Behandlingsinsatser som inkluderar självbestämmande och att stärka individens tilltro till sin egen förmåga kan vara viktiga delar för framgångsrik behandling av kvinnor med handikappande smärtor och käkfunktionsstörningar.
Beallediedalaš čoahkkáigeassu davvisámegillii

(abstract in North Sami)


Várka ja doaibmahehttejupmi mii dáhpáhuvaiv dávja geđaš-oalulvuogádagas (unnimusat oktii vahkus) leai 17 % sis geat oassálastet jearahallanguorahallamis. Dévjes oaiivebákčasa diedihedje 19% ja várrkka niskkis/oalggis 30 %. Chíežanuppleohkái proseanta oppa nissonjoavkkkus diedihedje ahte dápndamearkkat geđaš-oalulvuogádagas váikkukedje sin beaviválaš eallima negatiivvalaččat. Olu nissonat diedihedje dápndamearkkaid juohke guorahallojuvvon oasís, mii mearkkaša ahte buohccivuodat doibmet oktasaččat. Várka olloliin leai deataleamus go sii meroštallet mii dápndamearkkaid váikkukhi eanamusat sin beaviválaš doaimmaide, muhto mearkkašupmi leai maiddái jus sis leai váílevaš níalmii cakkastandáási, várka niskkis/oalggis ja vuollegis oahpahusdáási. Visot nissonat geain leai guhkálaš, garra ja dávjas várka ja doaibmahehttejupmi geđaš-oalulvuogádagas bovdejuvvojedje klinikhalaš guorahallamii 2 jagi manjel jearahallanguorahallama: 22 TMD nissona (ásší) ja 46 nissona geat lejde seamma agis ja geain eai lean dápndamearkkat geđaš-oalulvuogádagas (buohtastahti) oassálaste.


Díkšunstrategiijat mat siskkildit iešmearrideami ja mat nannejit oktonas olбо jāhku iežas návccaide sáhttet leat deatalaš oasit buori buohceddikšumis nissoniidda geain leat várkkat mat hehttejit sin doaimmaid ja váilevaš geadaš-oaululvuogádatdoaimmat.

Translation:
Professor Mikael Svonni, UiT, The Arctic University of Norway
Original papers

This doctoral thesis is based on the following original papers, which will be referred to in the text by their Roman numerals:


The papers are reprinted with the kind permission of the publishers; Informa Healthcare, London (papers I and II), and Quintessence Publishing Company Inc, Chicago (papers III and IV).
Preface

As I recall, it was a warm and sunny Easter day. I was resting on a reindeer skin, in a snowdrift; a fire crackled, and my thoughts happened to be in the deep woods surrounding Lake Inari in Finland. I had a break in the middle of the 5th semester of my dental education, and my teacher in clinical oral physiology had sent me off with a thesis, so I had “something to do during the Easter holidays,” since the curriculum did not have any leisure, but “time to read.” So far, it had been the most interesting course in the dental program, and although I was still not sure about the choice of dental career, this was while sitting on that reindeer skin that I decided to continue on with the program. It was time to decide on a graduation project, and I believe the teacher thought that the Helkimo study on Skolt and Inari Samis in Finland would inspire me, since I was Sami myself. I had previously studied Sami culture, history, and language at the University, and thought it might be a suitable project, combining my choice of occupation with a project within a Sami context. Easter was celebrated as usual, up in the mountains, at the finest place I know, Rautasjaure, the birthplace of my grandparents and ancestors. Like the Sami women who came to participate in my research, I gather strength and energy in a place far away from modernity, such as electricity, running water, and mobile phone coverage. Perhaps it is my Sami heritage that raises my longing to be away from civilization at some point every year, to find peace of mind.

Being able to finish this PhD has at times felt quite impossible, because of ill health, which meant long periods of sick leave. Many times I have thought that I wouldn’t manage to complete the project, but the work of this thesis has often been a great way to dispel those thoughts, when life has been extra tough. Illness sometimes leads to other perspectives, and I thought a lot during those periods about how I wanted my career to develop. I decided to study further to become a specialist in clinical oral physiology. Thus, any interruption in the PhD program, I cannot ascribe to illness. There were also positive events such as the three-year specialist training, and the biggest and best event in my life, becoming a mother. I took as much maternal leave as I possibly could.

My research started with questions about the prevalence of temporomandibular disorders (TMD) in the Sami population, since the prevalence was high in the Helkimo study compared to that of other populations. Another perspective was related to the question why women dominate as patients referred for treatment. Today, these patients constitute my everyday life as a specialist. Combining the quantitative study with a qualitative
approach made it possible to obtain a deeper knowledge of individuals’ experiences, in my wish to find reasons why women are more affected by TMD than men. I believe that the answer is complex and may be found in the biopsychosocial model. Our social context probably has a greater significance for the way we handle things than we normally realize. Perspectives on a condition may be widened when quantitative and qualitative research methods are combined. In my opinion, one method is not better or worse than the other; rather, they should be seen as complementary to each other, and it has been educational to use both.

The cover photo is from my paradise, Rautasjauré, the mountain called "nieidabákti" (girl mountain).


~ Ur boken Bortom fjällen av Ernst Manker, 1957

I hope you will enjoy this reading as much I have enjoyed writing it.

Umeå, September 2014

Christina Storm Mienna
Introduction

The Sami population

The Samis are the Indigenous people in Sweden, Norway, Finland, and Kola Peninsula in Russia. In 1977, the Swedish Parliament recognized the indigenous status of the Sami. Since 2011 the Sami are recognized as a people in the Swedish constitution. The Sami people have historically lived in the region called Sápmi (Samiland), which overlaps the borders of four nations (Figure 1).

![Map of Sápmi](image)

**Figure 1:** Map of Sápmi. Reprinted and adjusted with permission from Nordiska museet, Stockholm.

Studies of genetic markers in the Sami people over four decades have shown that they are genetically unique compared to other populations studied (Beckman 1996). The relatively homogeneous genetic composition of the Samis, combined with a shared cultural heritage, make them suitable for studies related to development of diseases with a multifactorial background (Johansson et al. 2005).

A detailed census of the Sami people has not taken place, as ethnic markers are forbidden in national population registers, as regulated by Swedish laws. It is estimated that there are about 85 000 Samis altogether, of whom approximately 20 000 live in Sweden and of whom 2500 work full-time with reindeer herding (Solbakk 2006). However, the Sami population in Sweden may consist of as many as 40 000–50 000 individuals, according to a
constructed database on health and living conditions (Hassler et al. 2004a). About 50% of the total Sami population in Sweden lives in the northernmost county, Norrbotten (Sjölander 2011). For the Sami people, reindeer herding, fishing, hunting, and handicrafts were historically traditional ways of life (Solbakk 2006). Today most Sami participate as an integrated part in various professions and economic activities in society. They have been assimilated into a western lifestyle and thereby share the accompanying diseases (Hassler et al. 2005).

Knowledge of the Sami health situation in Sweden is fairly limited, but during the last decade several studies mainly based on data from national registers, have been published. The Southern Lapland Research Department in Vilhelmina has accounted for improvements in the knowledge of the Sami people’s health situation in Sweden. Despite these efforts, Sweden is still far behind Norway, where governmental resources have been allocated for research on the health situation of their Indigenous people, the Samis. In 2007, the United Nations special rapporteur Paul Hunt (Hunt 2007) recommended that the Swedish government support the establishment of a Sami Health research centre, as in Norway; he also suggested that the Swedish government should “consider establishing a body within the Ministry of Health with national responsibility for oversight of Sami health”. Hitherto, no such unit has been established in Sweden. During 2013 Västerbotten County Council applied to the Swedish government to start a national Sami Healthcare center. If this becomes reality, related resources may help to conduct further research on the Sami population’s health conditions.

In general terms the health and living conditions of the Samis, in comparison with other Indigenous peoples (Sjölander 2011), seem to be good and essentially similar to that of the Swedish general population. Some differences have nevertheless been observed. Cancer is the disease that has been most thoroughly studied in the Sami population (Sjölander 2011). The risk of developing and dying from cancer was lower among the Sami compared to general populations in Norway, Sweden, and Finland. Plausible explanations were lifestyle-related factors, including dietary components and physical activity (Hassler et al. 2008a, Hassler et al. 2008b). Gender differences in cardiovascular disease among the Sami have been reported. Sami women showed an increased risk for mortality from subarachnoid haemorrhage and ischemic heart diseases (Hassler et al. 2005). Among women from reindeer-herding families, and for Sami men not involving in reindeer herding, an increased risk of stroke has been reported. The incidence of stroke was significantly increased for both Sami men and women who had adopted a more westernized lifestyle (Sjölander et al.
2008b). Sami women, particular those of reindeer-breeding families, were more exposed than men to psychosocial risk factors, such as lower decision-making latitude, social support, and intellectual discretion. Differences in exposure to behavioral and biomedical risk factors can partly account for the gender difference between Sami men and women (Edin-Liljegren et al. 2004). Musculoskeletal symptoms have been highly observed among both men and women in reindeer-herding families. In men, the use of terrain vehicles was the main cause (Daerga et al. 2004, Näyhä et al. 1991, Sjölander et al. 2008a), with a higher risk for fatal accidents (Hassler et al. 2004b). In women, on the other hand, the musculoskeletal symptoms seemed to be related to psychosocial factors such as poor social support, high effort, low reward, and high financial responsibilities.

Temperomandibular disorders

Terminology

The jaw system is essential for survival, and is involved in basic functions such as mastication, biting, tasting, swallowing, respiration, and speech. These functions engage the mandible, the teeth, the tongue, the cheeks, the temperomandibular joint (TMJ), the skull, the upper part of the spinal column, the jaw-and neck muscles, the salivary glands, the nervous system, and blood supply. A disturbance in any of these parts may thus affect the functions of the jaw system and the quality of life.

In 1934, an otolaryngologist, Dr. James Costen (Costen 1934), described symptoms from around the ear and the temperomandibular joint, which he attributed to the dental occlusion; the term Costen’s syndrome was coined. Different ways to designate functional disturbances of the masticatory system have since been advocated; temperomandibular joint dysfunction syndrome, occlusomandibular disturbances, myoarthropathy of the temperomandibular joint, myofascial pain dysfunction syndrome, temperomandibular pain dysfunction syndrome, mandibular dysfunction, internal derangements of the temperomandibular joint, and so on. The different terms describe various views of the possible origin and main feature of the condition; some focus on dysfunction and others emphasize pain. These terms were in the 1980s included under the broader concept craniomandibular disorders, and from the 1990s onwards the most commonly used expression in the literature is temperomandibular disorders (Okeson 2008).
Temporomandibular disorders (TMD) is a collective term embracing a cluster of related disorders in the masticatory system, with common symptoms (Drangsholt and LeResche 1999) and clinical problems involving muscles, the TMJ, the occlusion, the nervous system, and associated structures (de Leeuw 2008). In 1983, the American Dental Association, (Drangsholt and LeResche 1999) characterized TMD as a condition with pain in the TMJ region and/or in the jaw muscles during function, limitation in mandibular range of motion and/or TMJ sounds during jaw function. TMD can be regarded as musculoskeletal disorders in the jaw–face region, since it resembles other musculoskeletal disorders and chronic pain conditions.

Classification

Different systems have been advocated over the years to classify signs and symptoms of TMD in attempts to systematically standardize definitions for classifying or stating a diagnosis of TMD conditions (Fricton and Schiffman 1986, Lundeen et al. 1986, Dworkin and LeResche 1992,). In my doctoral thesis two models for classification of TMD were used; the anamnestic (Ai) and clinical dysfunction (Di) indices as devised by Helkimo (Helkimo 1974b) and the Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD) (Dworkin and LeResche 1992). The anamnestic dysfunction index was developed to classify reported symptoms in three grades based on expected severity: Ai 0 = symptom-free, Ai I = mild symptoms (jaw tiredness and TMJ sounds), and A II = severe symptoms (TMJ locking, difficulties in opening wide and jaw pain). The clinical dysfunction index was based on the outcome of a clinical examination that measures range of mandibular movement, function of the temporomandibular joint, presence of pain on movements of the mandible, presence of muscle pain, and/or temporomandibular joint pain to palpation. Each variable examined is scored on three levels of severity based on defined criteria: no signs of dysfunction (0 points), mild signs of dysfunction (1 point), and severe signs of dysfunction (5 points). The sum of the scores can thus range from 0 to 25 points. The index is constructed as an ordinal scale in four grades of severity: no signs of dysfunction (Di 0), mild signs of dysfunction (1–4 points, Di I), moderate signs of dysfunction (5–9 points, Di II), and severe signs of dysfunction (10–25 points, Di III).

RDC/TMD was developed for clinical and epidemiological research purposes to provide standardized diagnostic classifications of the most common TMD conditions (Dworkin and LeResche 1992). Axis I is a non-hierarchical diagnostic scheme, and a condition can be diagnosed into one of three main groups: (1) muscle disorders (2) disc displacements, and (3) arthralgia, arthritis, and arthrosis. The RDC/TMD Axis II classification system included
pain-related disability and psychological status (Dworkin and LeResche 1992). The classification system has recently been revised to Diagnostic Criteria of TMD (DC/TMD), aimed for clinical use (Schiffman et al. 2014).

**Etiology**

The etiology of TMD is complex and, multifactorial, and has been debated over the years. One more recently advocated perspective is summarized in a biopsychosocial model (Suvinen et al. 2005). Parker presented in 1990 a dynamic model to depict the etiology. He proposed that there was a balance in the masticatory system between destructive, overloading factors and adaptive factors. Factors such as trauma, health/nutrition, the musculoskeletal structure, coping strategies, and gender might increase or decrease a patient’s adaptability. Life stressors, sleep disorders, pain/depression, occlusion, and posture were proposed as predisposing factors to dysfunction (Parker 1990).

Structural damage of the TMJ has also been proposed, because it changes physical properties and may alter the ability to withstand loading forces (Stegenga et al. 1991). In a similar perspective on the etiology of TMD, the balance between load and capacity of the involved structures has been advocated (Wänman and Agerberg 1991). Since no single factor has been identified as a sufficient or necessary etiological factor, it may be more relevant to describe them as contributing factors (De Boever and Carlsson 1994). These contributing factors have been classified as predisposing, initiating, and perpetuating. Those that increase the risk of developing TMD are regarded as predisposing factors, and it has been proposed that they be subdivided into *systemic* (e.g. inflammatory or degenerative diseases); *psychological*, such as personality, behavior, and mood disturbances; and *structural*, such as different types of occlusal discrepancies and joint laxity. Initiation factors are those that induce onset of TMD, and such proposed factors are micro and macro trauma, and adverse or excessive loading of joint structures, including parafuncions such as bruxism (De Boever and Carlsson 1994). Factors that interfere with healing or enhance the progression of TMD are referred to as perpetuating factors, which may be divided into *local* (parafunctions and posture) and *systemic* such as behavioral, social, emotional and cognitive factors (De Boever and Carlsson 1994, Okeson 2008). Occlusal factors, such as mandibular instability, and cross bite have been reported as possible candidates in relation to perpetuation of TMD (Kirveskari and Alanen 1984, De Boever et al. 2000, Marklund and Wänman 2010a). Conflicting results exist regarding the importance of dental occlusion in relation to the etiology of TMD. In a review (Türp and Schindler 2012), bruxism, loss of posterior support, and unilateral
posterior cross bite showed some possible relationship to TMD, but the authors also pointed out that disturbances in the occlusion may be a consequence of TMD and not its cause. In a recent study, the authors concluded that malocclusion and loss of five or more posterior teeth did not contribute to TMD (Sousa et al. 2014).

It is likely that many conditions can affect the function of the jaw system and the individual response also depends on several factors that make research in etiology both difficult and demanding.

**Epidemiology**

Epidemiological methods can be used to identify how common a condition is in a population as well as its natural course if it is left untreated, and to assess risk factors for onset and perpetuation. Cross-sectional studies based on representative samples of a population are usually conducted to determine the prevalence of the problem in focus. Prevalence is defined as the number of persons with the condition at a specific time divided by the total size of that population. Knowledge of the prevalence can help to determine the magnitude of a health problem and its burden on the individual and the society (Drangsholt and LeResche 1999).

Early clinical studies of TMD indicated that it is a common, heterogeneous pain disorder, primarily afflicting women aged 20–45 years (Helkimo 1976). In 1972, the first epidemiological study of dysfunction of the masticatory system was published (Helkimo et al. 1972). Helkimo performed a cross-sectional study on 245 Skolt- and 76 Inari-Lapps in the north of Finland and used the Ai and Di indices for descriptive purposes (Helkimo 1974b). He observed that signs and symptoms of mandibular dysfunction were common in this Sami population; 88% had one or more signs and 57% had symptoms of mandibular dysfunction. He estimated that approximately 25% of this population had need for treatment, since 22% had severe signs and 26% had severe symptoms according to the indices (Helkimo 1974a). Despite a large number of subsequent studies in different populations, none has since reached the high prevalence found in Helkimo’s study on a Sami population in Finland. Partly from this perspective it was interesting to conduct a new study on a Sami population.

The prevalence of TMD signs and symptoms varies, depending on methodology and population (Nydell et al. 1994). A review from 1984, arrived at a median value of one out of three for TMD symptoms and two out of three for TMD signs and found a large variation between different studies (Carlsson 1984). The prevalence of TMD symptoms was 20% and 50% had
TMD signs in a Dutch population (De Kanter et al. 1993). Salonen et al. reported similar results based on a Swedish population (Salonen et al. 1990). Jagger et al. reported a prevalence of TMD in an indigenous Ecuadorian population similar to that of Scandinavian samples (Jagger et al. 2004). An increase in prevalence of symptoms indicative of TMD during a 20-year period has been observed (Anastassaki et al. 2012). It has been proposed that psychosocial health determinants are involved in the observed time trend (Anastassaki and Magnusson 2004). In a review of TMD pain, approximately one out of three adults was predicted to develop TMD pain during their lifetime (Drangsholt and LeResche 1999).

The prevalence of severe TMD symptoms is rare in young individuals (Anastassaki et al. 2009), but increases during the adolescent period (Nilsson et al. 2009). Longitudinal studies have shown that both signs and symptoms of TMD fluctuate over time (Magnusson et al. 1985, Wänman 1987, Könönen and Nyström 1993, Marklund and Wänman 2010a). Several population-based studies on TMD pain and headaches have observed a declining prevalence with age (Salonen et al. 1990, Österberg and Carlsson 2007, Carlsson et al. 2014), with older individuals reporting TMD symptoms less often than younger ones. The reason behind this observation is not known. In a sample of 90-year-olds, signs and symptoms of TMD were predominately of mild character and infrequent, except for TMJ crepitation (Tzakis et al. 1994). In a cross-sectional study including 70- and 80-year-olds, 6-10%, reported some, and 1-2% rather great or severe problems of TMD pain (Carlsson et al. 2014). TMD symptoms were also rarely reported among another sample of 70-year-olds (Österberg and Carlsson 2007). In a recent population-based study the prevalence of frequent symptoms indicative of TMD peaked among 50-year-old women and then declined in the more elderly women (Yekkalam and Wänman 2014a). Johansson et al., on the other hand, reported no differences in prevalence of TMD symptoms between 50 and 60 years of age in a 10-year follow-up study (Johansson et al. 2003).

**Gender differences**

It has generally been reported that women have more signs and symptoms of TMD than men, but no major difference in the prevalence of mandibular dysfunction was found between men and women in the Sami population in northern Finland. Only a few symptoms differed in prevalence with gender, with significantly higher prevalence of headache, NSP and feelings of fatigue in the jaws in Sami women (Helkimo 1974c).
Cross-sectional studies on samples from general populations have found varying proportions of men and women relative to prevalence of TMD. One reason may be related to inclusion criteria of symptoms—their frequency, intensity, and duration. Among patients with TMD, women outnumber men, with more women seeking treatment and being referred to consultants. For referrals to specialist TMD clinics, commonly reported ratios of women-to-men are 3:1, and the majority of patients are between 20 and 40 years of age (Anastassaki and Magnusson 2004). In a sample drawn from the general population, 50-year-old women reported significant higher prevalence of symptoms indicative of TMD than men of the same age, no gender differences were found in 65- to 75-year-olds (Yekkalam and Wänman 2014a). In a prospective study over approximately 10 years, women showed a longer duration of TMD symptoms compared to men (Wänman 1996). Different courses of TMD symptoms between men and women indicate that women may be less likely to recover from these conditions, although fluctuations of symptoms occurred among both men and women during the observation period. Other differences in the TMD symptom’s quality, such as its frequency, intensity, and effect on quality of life, may also be factors of importance related to utilization of health care.

Sex-related differences have been observed in both clinical and experimentally induced pain studies (Fillingim 2000). In a review, of gender variations in pain experience (Unruh 1996), it was suggested that women are more likely than men to experience a variety of recurrent pains. Women report more severe pain levels, more frequent pain, and pain of longer duration than men do. Women may also be at greater risk for pain-related disability than men. Gender variation in coping strategies was also found. It has been suggested that women develop coping strategies that include active behavioral and cognitive coping, avoidance, emotion-focused coping, seeking social support, relaxation, and distraction. Men instead seem to use strategies including talking problems down, denial, looking on the bright side of life, and tension-reducing activities such as alcohol consumption, smoking, and drug abuse. Gender differences in brain chemistry, metabolism, physical structures, and hormone variations may influence the biological mechanisms of pain transmission, sensitivity, and perception. Sociological and psychological factors, culture, and ethnicity may also influence pain perception and behavior. Women with multiple responsibilities such as childcare, household management, and full or part-time employment may have more than one reason to apprehend pain as a threatening condition. Men may perceive pain as being of limited importance unless it interferes with their work. These factors may be important in understanding pain and disability in a population, and since there may be gender-related influences of TMD, it has been proposed that
men and women should be studied separately in research of contributing factors to TMD (Wänman 1996, Henrikson 1999). Women and men may also differ in their recovery from pain and may therefore require different interventions (Unruh 1996).

**Co-morbidity**

Several studies have demonstrated co-morbidity between TMD, headaches, NSP, and back pain. (Schokker et al. 1990, Ciancaglini and Radaelli 2001, Visscher et al. 2001b, Rantala et al. 2003, Wiesinger et al. 2007,). Headache is a common condition in the population and has been associated with signs and symptoms of TMD (Wänman and Agerberg 1987, Cooper and Kleinberg 2009, Marklund et al. 2014). Headaches are more commonly reported by women than by men after childhood (Rasmussen et al. 1991). There is a relationship between TMD and muscle tenderness. In an epidemiological study of 35-year-olds the subjects were grouped according to patterns of muscle pain to palpation. Those who had tender sites to palpation at both neck and jaw muscles, together with those who showed a pattern of more generalized hyperalgesia, had significantly higher prevalence of signs and symptoms of TMD than other groups (Wänman 1995). In addition to the relationship between pain in jaw and neck muscles, there is also a functional relationship between these regions. Thus, during jaw function such as opening and closing, an integrated pattern between the jaw and head movements has been observed (Eriksson et al. 1998, Eriksson et al. 2000).

Individuals with symptoms of TMD have also in several studies reported impaired general health status (Agerberg and Carlsson 1975, Johansson et al. 2004, Österberg and Carlsson 2007, Carlsson et al. 2014). Central and peripheral sensitization mechanisms are involved in pain perception (Sarlani et al. 2004) and may induce spread of pain to the jaw–face area from other regions, such as back, chest, and stomach. (John et al. 2003). Stimulation of either the trigeminal or the spinal area affects the other, as has been shown in experimental pain studies (Hellström et al. 2000, Komiyama et al. 2005). Taken together, these findings indicate that pain and dysfunction in the jaws, head, neck, and shoulders may influence each other and/or share the same contributing factors.

**Consequences**

It has been proposed that TMD pain is related to social factors such as unemployment and decreased work effectiveness (Drangsholt and LeResche 1999), and that individuals with chronic TMD pain had burdens, for society and the individual, similar to those of people with back pain, severe headache, and chest and abdominal pain, including psychological distress.
and, economic costs for society and the patient (Drangsholt and LeResche 1999). Other studies have shown negative consequences for individuals, such as having spent a lot of money for treatment, or lost their jobs, and even their houses and belongings (Garro et al. 1994). The costs for society due to TMD pain include costs of providing care and costs associated with work loss and decreased productivity of work. In a study from Finland a sample, drawn from keyboard operators in an industry with NSP, were randomly referred to either a treatment or a non-treatment group. The treatment was directed towards stabilization of the mandible, with selective tooth grinding, and in some cases, bite-splints. Both groups averaged 33 days of sick leave the year before the study started. One year after, the treatment group showed an average reduction of 11 days, while the non-treatment group had a slight increase of sick-leave days (Kirveskari and Alanen 1984). In a review (Dahlström and Carlsson 2010) it was shown that oral health-related quality of life (OHRQoL) was negatively affected among TMD patients. Studies on TMD are from this point of view important for both the individuals and for society.

**Mixed methods**

A combination of quantitative and qualitative methodology can give new perspectives from both approaches. Epidemiological studies with a quantitative approach can add knowledge about incidence, prevalence, natural history of diseases, and determinants. To capture a deeper understanding about experiences, attitudes, norms, knowledge, and behavior, qualitative approaches are more suited. Qualitative studies are rooted in traditions from the disciplines of anthropology, sociology, and psychology (Polit and Beck 2006). One commonly used description of a qualitative approach is “an inquiry process of understanding based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting” (Creswell 1998). Three basic types of mixed method designs are described: convergent, sequential, and embedded. These are termed differently by different authors, but the main procedures are equivalent (Creswell 2003, Klassen et al. 2012, Zhang and Creswell 2013). This thesis has used a sequential design where collection and analysis of the quantitative data was followed by the collection and analysis of the qualitative data, to elaborate on and expand the findings of one method with another. There are different tools for collecting qualitative information, such as in-depth interviews, observations, and focus group discussions. In this thesis interviews were used to collect qualitative data.
**Grounded theory**

Grounded theory (GT), a common method mostly used for designing and analyzing of qualitative data, was used in this thesis. The method was developed in sociology during the late 1960s (Glaser and Strauss 1967), with its theoretical roots in symbolic interactionism, a social psychological perspective where the society is regarded as a sum of all ongoing interactions and events, and a process that is constantly changing and not a permanent structure. It is thus process-oriented, as reality is considered to be fluid and constantly created and modified (Morse 1992). The goal in GT is to generate comprehensive explanations of phenomena that are grounded in reality (Polit and Beck 2006), to generate a theory that explains a pattern relevant to the participants involved in the study. Key features of doing GT are an emergent design and constant comparisons (Dahlgren et al. 2004).

**Trustworthiness in qualitative research**

The criteria of trustworthiness in qualitative and quantitative research capture similarities between the traditions, but have different terms because of differences in applications and interpretations, as indicated below.

*Credibility* refers to the ability to capture the multiple realities of those under study. In quantitative research the related term is *internal validity*, which refers to the ability to capture the truth value (have you measured what you meant to measure?).

*Transferability* refers to whether the knowledge can be transferred to other contexts. The knowledge gained from a developed theory should fit different scenarios that may occur in larger populations. The term for the same issue in quantitative research is *external validity*, or ability to generalize (how applicable are the results to other contexts?).

*Dependability* refers to the ability of the researcher to account for constantly changing conditions of the phenomenon under study, for the interaction with the participants, and for the emergent designed process. The term in quantitative research is *reliability*, and it refers to, whether the research result can be replicated in the same context with the same sample.

*Confirmability* refers to neutrality of the data rather than neutrality of the researcher. In qualitative research the interaction between the researcher and the participant is important, and a basis for credibility. The related term in qualitative research, *objectivity*, or neutrality refers to the ability to have
distance from the observed phenomenon, to be objective and to not impose any effect on the study related to personal interests.

GT criteria for trustworthiness are somewhat different (Glaser and Strauss 1967), and are termed fitness, workability, relevance, and modifiability, meaning that a theory fits when the categories fit the data and a theory works when it is able to explain what is happening in reality or at a conceptual level. A theory has relevance when the core problem according to the informant is interpreted in natural ways, as in GT. A theory can be changed in response to a changing world; it is in that way modifiable (Dahlgren et al. 2004).

**Rationale**

The high prevalence of TMD signs and symptoms, together with a predominantly fluctuating pattern of the condition, has called into question the validity of epidemiological findings. From the clinical perspective, women outnumber men as patients for these disturbances; the reasons for this globally found pattern are not completely understood. It is essential not to rely solely on patient samples when examining the associated and contributing factors of a certain disease, because various elements may influence a patient’s decision to seek health care. Therefore, samples drawn from the general population are needed, not only to determine the prevalence or incidence of a certain condition in a population, but also to explore possible co-morbidities and relationships. Since pain and dysfunction in the jaw–face/head–neck region may be related to gender, it has been proposed that men and women should be studied separately in research of etiology. Gender, biological and psychological factors, culture, and ethnicity may also influence pain perception and behavior and are important in the understanding of pain and disability in a population. A qualitative approach can help to get deeper insight in individual’s experiences and thoughts about having longstanding dysfunction and pain symptoms.
Aims

The overall objective of this thesis was to investigate prevalence of signs and symptoms indicative of TMD and factors related to perpetuation of dysfunction and pain in the jaw-face, head, neck-shoulder region and its impact on well-being in a defined population of Sami women. The aim was also to gain deeper insight into experiences, attitudes, and beliefs among women with longstanding TMD.

Specific aims:

Paper I:
- To study the prevalence, frequency, intensity, duration and co-morbidity of symptoms indicative of TMD, headaches, and neck-shoulder pain in a defined population of Sami women.

Paper II:
- To validate self-reported longstanding, intense, and frequent symptoms of pain and dysfunction in the jaw-face region in relation to RDC/TMD diagnosis and clinical signs of dysfunction at a two-year follow-up.
- To compare women with TMD (cases) to women without TMD (controls) with regard to dental occlusion, general health, and awareness of oral parafunctions.

Paper III:
- To examine the influence of frequency, intensity, and duration of TMD, headaches, and neck-shoulder pain on activities of daily living (ADL).
- To analyze symptoms indicative of TMD, headaches, and NSP in relation to age.

Paper IV:
- To explore thoughts, experiences, and beliefs regarding TMD among Sami women with and without TMD.
- To gain insight into Sami women’s health care experiences.
- To generate hypotheses regarding factors associated with longstanding TMD.
Study population and methods

This doctoral thesis is based on three sub-studies, published in four papers. To achieve the overall aim of the study a mixed methods approach was used. Two papers are cross-sectional epidemiological studies, based on the subjects’ response to a questionnaire (Papers I and III). Paper II is a prospective case–control study based on a sub-sample of the former epidemiological sample including a blinded clinical examination. Paper IV is based on a qualitative method with thematic interviews using a grounded theory approach on a strategic selected sample drawn from the study of Paper II (Table 1). A flowchart over the study populations is presented in Figure 2.

Table 1. Brief presentation of the study population and methods used.

<table>
<thead>
<tr>
<th>Study design</th>
<th>Paper I</th>
<th>Paper II</th>
<th>Paper III</th>
<th>Paper IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data collection</td>
<td>Cross-sectional observational study</td>
<td>2-year prospective, age-matched, case and control study</td>
<td>Cross-sectional observational study</td>
<td>Qualitative study</td>
</tr>
<tr>
<td>Sample characteristics</td>
<td>Sami women aged 21–70 years in Sweden (n = 487)</td>
<td>Sami women with (n = 22) and without (n = 46) longstanding symptoms indicative of TMD</td>
<td>Sami women aged 21–70 years in Sweden (n = 487)</td>
<td>17 informants drawn strategically from Paper II</td>
</tr>
<tr>
<td>Data analysis</td>
<td>Binary logistic regression (Mantel–Haenszel estimates of odds ratio)</td>
<td>Chi-square test, Fisher’s exact test, t-test, Wilcoxon’s signed matched test, binary logistic regression</td>
<td>Multiple logistic regression, chi-square test</td>
<td>Transcribed textfiles, analysis based on grounded theory</td>
</tr>
</tbody>
</table>
Study population

Papers I and III

The inclusion criteria for the questionnaire study were women living in the communities of Kiruna or Gällivare, in the county of Norrbotten, in the Arctic region of Sweden. To be included they had to be registered in the electoral register of the Swedish Sami Parliament for 1997, or in the register of the Swedish Board of Agriculture as reindeer owners or reindeer herders. In the electoral register from 1997, 5991 individuals were registered compared to 8322 individuals in the register from 2013. The electoral participation has decreased from 63% (1997) to 54% (2013).
The Sami Parliament Act (SFS1992:1433, Sametingslagen), states the criteria a person must meet to have the right to vote in the Sami Parliament of Sweden:

- any person who considers themselves to be Sami; and
- uses or has used the Sami language at home, or
- can show that one of his or her parents or grandparents uses or used the Sami language at home, or
- has a parent who is or has been listed in the electoral register of the Sami Parliament

At the time of the data selection (year 2000) the women included in the study were between 21 and 70 years of age. The Southern Lapland Research Department in Vilhelmina assisted in defining and selecting the sample. A total of 751 Sami women fulfilled the inclusion criteria and were sent a questionnaire.

Respondents and dropouts

Altogether, 487 females (65%) responded and returned the questionnaire. Their mean age was 40.2 years (SD 12.9). In total, nine questionnaires were returned undelivered, one because the respondent had deceased, and a further twelve were returned blank (Table 2).

Dropout analysis

Out of those individuals who did not participate, every third one in each 10-year age-cluster, was selected for a dropout analysis. A total of 53 women were contacted for an interview by telephone, of whom 30 women agreed to answer a few selected questions from the questionnaire. The most common reasons given for not participating were “out of principle” (38%) and “for no particular reason” (25%). Other answers were that they “had no time to fill out the questionnaire” (11%), did not consider themselves to be Sami (9%), had been away from their home address (8%), felt the study was discriminatory (4%), had no symptoms (4%) or were severely ill (2%).

The prevalence of symptoms of TMD among the drop-out sample was 33% and two out of three reported NSP. No significant differences in prevalence of the symptoms examined were found between the dropouts and the participants (Table 2).
Table 2. Number of sample, participants and dropouts among Sami women in different age group.

<table>
<thead>
<tr>
<th></th>
<th>21–30 yrs</th>
<th>31–40 yrs</th>
<th>41–50 yrs</th>
<th>51–60 yrs</th>
<th>61–70 yrs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample</td>
<td>116</td>
<td>168</td>
<td>176</td>
<td>169</td>
<td>122</td>
<td>751</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Deceased</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Returned blank</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Participants</td>
<td>82</td>
<td>116</td>
<td>117</td>
<td>105</td>
<td>67</td>
<td>487</td>
</tr>
<tr>
<td>Dropouts</td>
<td>34</td>
<td>48</td>
<td>54</td>
<td>59</td>
<td>47</td>
<td>242</td>
</tr>
<tr>
<td>Dropout sample</td>
<td>11</td>
<td>16</td>
<td>17</td>
<td>19</td>
<td>15</td>
<td>78</td>
</tr>
<tr>
<td>Contacted</td>
<td>9</td>
<td>8</td>
<td>12</td>
<td>16</td>
<td>8</td>
<td>53</td>
</tr>
<tr>
<td>Phone interview</td>
<td>6</td>
<td>6</td>
<td>7</td>
<td>7</td>
<td>4</td>
<td>30</td>
</tr>
</tbody>
</table>

Paper II

For the follow-up study after two years, a sample of “cases” and “controls” was selected based on the answers from the first questionnaire. This study included 68 women between 23 and 72 years old.

TMD cases

The inclusion criteria to be identified as a case were, symptoms indicative of TMD, with a frequency of at least once a week, intensity level of 5 or more on an 11-point numerical rating scale (NRS), and a duration of at least one year. They should also have considered themselves to be Sami, in a specific question addressing that topic. A total of 35 women fulfilled the inclusion criteria and of these 18 women agreed to participate. In the oldest age group (63–72 years old), only one woman fulfilled the inclusion criteria. Therefore, to ensure that older ages also were represented, all women in this age group with symptoms indicative of TMD, and with a frequency of once a week or more and duration of at least one year, were included. Another five women fulfilled these inclusion criteria of whom four agreed to participate. One reported an intensity level of 8 on the NRS, two reported NRS 3, and one woman reported daily pains and feelings of tiredness in the jaws and a duration of more than 5 years, but had not filled in any intensity level on the questionnaire. The study thus included 22 Sami women classified as “cases”.
**Controls**

The criteria to be included as a “control” were that they considered themselves to be Sami, but did not report in the questionnaire any symptoms indicative of TMD or pain in the neck- or shoulder region. In total, 127 women fulfilled these inclusion criteria. The women were stratified into five age strata based on the base-line questionnaire (21–30, 31–40, 41–50, 51–60, and 61–70 years old). The oldest age-group comprised 28 individuals of whom 12 accepted participation, and the youngest age-groups comprised 16 individuals of whom four agreed to participate. In the other age-groups 16 women in each 10-year cluster were randomly selected. In total, 30 women in this group agreed to participate. The control group thus comprised 46 women.

**Dropouts**

The non-participating cases included ten women who had moved from the region, six women were not interested in participating, and one who was severely ill. The drop-outs from controls included, from the oldest age groups, seven women who did not want to be examined, four who could not be reached or traced, three who had no possibility of travelling to the dental clinic, one who had recently had a stroke with complications in locomotion, and one who was away from home. In the youngest sample, seven could not be reached or traced, and another five had moved. In the other age-groups ten subjects could not be reached or traced, four did not want to participate, two had moved, one could not travel to the clinic, and one had deceased.

**Paper IV**

For the qualitative thematic interview a purposive sample of informants with severe TMD as well as a sample without TMD was selected. The selection of informants was based on the answers in the two consecutive questionnaires and the outcome of the clinical examination.

Informants with severe TMD had persistent, longstanding, frequently occurring symptoms of TMD, with a reported intensity of 5 or more (NRS) for at least one symptom and with clinical signs confirming a diagnosis of TMD according to RDC/TMD. The other informants had no signs or symptoms of TMD. The women were informed at the clinical examination that they could be contacted again for an interview study. All of them agreed to be contacted.
Informants

In total 17 women participated in the thematic interviews. The social situation among the informants was not homogeneous regarding education level (comprehensive school to university), family situation (single to six family members) or working conditions (retired, unemployed, student, full-time worker). The characteristics regarding age, symptoms and diagnosis among the TMD informants are presented in Table 3.

Table 3. TMD informants’ age, symptoms, the symptoms stated impact on activities of daily living (ADL) with an 11-point numerical rating scale (NRS) and, clinical diagnosis according to RDC/TMD classification.

<table>
<thead>
<tr>
<th>Age</th>
<th>Symptoms in the jaw–face (ADL)</th>
<th>Other cephalic symptoms (ADL)</th>
<th>NSP (ADL)</th>
<th>Diagnosis RDC/TMD</th>
<th>Ai</th>
<th>Di</th>
</tr>
</thead>
<tbody>
<tr>
<td>58</td>
<td>Jaw pain, jaw tiredness, TMJ sounds and locking (5)</td>
<td>Headache (8) Tinnitus (5)</td>
<td>Neck &amp; Shoulder (9)</td>
<td>Myalgia Arthralgia Arthrosis DDwR</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>54</td>
<td>Jaw tiredness, TMJ sounds (3)</td>
<td>Headache (10) Tinnitus (2)</td>
<td>Neck &amp; Shoulder (10)</td>
<td>Myalgia</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>49</td>
<td>Jaw pain, jaw tiredness, TMJ sounds (7)</td>
<td>Headache (3) Tinnitus (5)</td>
<td>Shoulder (5)</td>
<td>DDwR</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>42</td>
<td>Jaw pain, jaw tiredness, TMJ sounds (7)</td>
<td>Headache (9) Tinnitus (6)</td>
<td>Neck &amp; Shoulder (9)</td>
<td>Myalgia</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>42</td>
<td>Jaw pain, TMJ sounds, jaw impairment (3)</td>
<td>Headache (5)</td>
<td>Neck &amp; Shoulder (3)</td>
<td>Myalgia DDwR</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>37</td>
<td>Jaw pain, jaw tiredness, TMJ sounds, jaw impairment (7)</td>
<td>Headache (6) Tinnitus (8)</td>
<td>Neck &amp; Shoulder (7)</td>
<td>Myalgia DDwR</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>36</td>
<td>Jaw pain, TMJ sounds (1)</td>
<td>Headache (3) Tinnitus (3)</td>
<td>Neck &amp; Shoulder (3)</td>
<td>Myalgia</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>29</td>
<td>Jaw pain, jaw tiredness, TMJ sounds, jaw impairment (5)</td>
<td>Headache (8)</td>
<td>Neck &amp; Shoulder (8)</td>
<td>Myalgia DDwR</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>29</td>
<td>Jaw pain, jaw tiredness, TMJ sounds and locking, jaw impairment (6)</td>
<td>Headache (8) Tinnitus (2)</td>
<td>Neck &amp; Shoulder (6)</td>
<td>Myalgia DDwR</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>23</td>
<td>Jaw pain, jaw tiredness, TMJ sounds, jaw impairment (4)</td>
<td>Headache (0) Tinnitus (2)</td>
<td>Neck &amp; Shoulder (6)</td>
<td>DDwR</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

TMD=temporomandibular disorders, RDC/TMD=Research diagnostic criteria for TMD, NSP=neck–shoulder pain, DDwR=disc displacement with reduction, Ai=anamnestic dysfunction index, Di=clinical dysfunction index, *=missing.
Methods

Questionnaire (Paper I and III)

A questionnaire concerning symptoms indicative of TMD, headaches, and NSP was sent to each woman’s home address, together with information and a pre-paid return envelope. The questionnaire focused on questions regarding frequency, duration, and intensity of the symptoms, and their impact on daily life (Appendix I). Seven weeks after the first letter had been sent, a reminder, along with a questionnaire, was sent to those who had not responded, and after a further four weeks a second reminder was sent out.

Frequency: Each question on symptoms had six possible response alternatives describing frequency: Never; No, not now but had it previously; Yes, at most once or twice a month; Yes, once a week; Yes, several times a week; Yes, daily. “Frequent symptom” was defined as a reported frequency of once a week or more.

Duration: To describe the duration, each symptom had four alternatives: less than 1 month; 1 month to 1 year; 1 year to 5 years; more than 5 years. “Longstanding symptom” was in this study defined as a reported duration of one year or longer.

Intensity: The intensity of symptoms was measured on an 11-point numerical rating scale (NRS).

Impact on activities on daily living (ADL): The impact of symptoms on ADL was measured by NRS; scales addressed headaches and NSP, respectively, and symptoms of TMD as a group.

Symptoms of pain and dysfunction in the jaw–face region were grouped in accordance with the index Ai devised by Helkimo.

The questionnaire also included open-ended questions regarding health care utilization, which are not included in the present thesis.

Clinical examination (Paper II)

A follow-up was conducted two years after the primary investigation. This included the same questionnaire as previously used, with a few additional questions and a clinical examination. Sixty-eight Sami women were invited to the clinical examination free of charge at one of the dental clinics in Karesuando, Kiruna, or Gällivare. Participants’ expenses for travel to and
from the clinic were reimbursed. A standardized clinical examination was performed by a specialist in TMD/orofacial pain who was blinded to the participants’ affiliation as a case or a control. The examination included:

**Dental occlusion:**
- Number of teeth (0–32)
- Overjet and overbite to the nearest mm
- Contact pattern in centric relation (unilateral or bilateral)
- Slide in centric in anterior–posterior, vertical, and lateral directions to the nearest 0.5 mm
- Tooth contact patterns at 3 mm and 9 mm lateral excursion of the mandible (anterior guidance, cuspid guidance, group function, balanced occlusion, laterotrusion side interference, mediotrusive side interference)
- Number of occluding pairs of teeth in intercuspal contact position (ICP), at light and hard clenching effort
- Supporting occlusal zones in accordance with Eichner (Eichner 1955, Österberg and Landt 1976), without removable dentures
- Presence of implant-supported fixed dental prosthesis

**Degree of tooth wear**
- Registered in accordance to Oilo (Oilo et al. 1987)

**Mandibular mobility**
- Unassisted maximal opening, protrusion, and laterotrusion measured to the nearest millimeter with a ruler (Agerberg 1974)

**TMJ signs**
- TMJ sounds. Auscultation, without a stethoscope, for the presence of TMJ sounds on opening and closing movements of the jaw. The occurrence of sounds was classified as sharp clicking, dull clicking, or crepitating.
- TMJ tenderness. The TMJ was palpated laterally and posteriorly through the auditory meatus. Pain was registered only if the palpation elicited a palpebral reflex in the eye or a protective reflex (withdrawal).
- TMJ pain on unassisted jaw movements (opening wide, laterotrusion, protrusion)
- TMJ loading. The subject was asked to bite hard for 30 seconds on a double wooden spatula (3 mm) placed on the region of the first molars, each side separately. Elicited pain in the contralateral side of the joint was registered as TMJ load pain.
• TMJ joint play. The examiner’s first finger on the right hand was placed on the participants’ left molar region. While holding the mandible, it was pulled forwards and backwards with the operator’s third finger on the left hand placed over the left TMJ. The TMJ movement was registered if restricted, painful, or both. The procedure was repeated on the other side.

**Muscle signs**

• Muscle tenderness. Presence of pain to palpation of muscle sites. Pain was registered only if the palpation elicited a palpebral reflex in the eye or a protective reflex (withdrawal). The following sites were palpated: region of the lateral pterygoid muscles, medial pterygoid muscles, anterior and posterior parts of temporal muscles, tendon of the temporal muscles, superficial and deep parts of masseter muscles, sternocleidomastoid muscles, trapezius muscles, neck muscles in the region of linea nuchae and thumb muscles. If the latter elicited a pain response, the muscles on the underside of the forearms and the calf muscles were also palpated to measure signs of a generalized pain response (hyperalgesia) to palpation.

• Static loading of jaw muscles. The participant was asked to clench her teeth hard in the intercuspal position for 30 seconds. Development of feeling of tiredness/fatigue or pain in the head, face, or jaws during clenching was registered.

**Perception thresholds**

• The perception over the areas innervated by the trigeminal nerve was tested with von Frey filaments. The following areas were tested on the right- and left-hand sides: the forehead, the infraorbital region, the cheek, the mental region, and the temple.

**Body Mass Index (BMI)**

• Weight and height for calculating the BMI.

Some of the variables collected in the questionnaire and some of the variables registered clinically were used to calculate the anamnestic dysfunction index (Ai) and the clinical dysfunction index (Di), respectively (Helkimo 1974b). A classification of each participant was also done in accordance to RDC/TMD Axis I (Dworkin and LeResche 1992).
**Statistical methods (Papers I-III)**

The questionnaire data were first transferred into a data-base (EpiInfo) and then converted into SPSS ver. 12.0 (Paper I) ver. 14.0 (Paper II) ver. 17.0 (Paper III) for Windows. The level of statistical significance was set to a P-value < 0.05 (Papers I–III).

**Paper I**

Binary logistic regression by Mantel–Haenszel estimates of odds ratio (OR) and 95% confidence interval (CI) were used.

**Paper II**

Comparisons between cases and controls with regard to categorical variables were done using the chi-square test or Fisher’s exact test if the expected counts were less than 5. Comparisons between groups with regard to continuous variables were done using the t-test for independent samples. Comparisons of registrations within cases and controls at the first and second examination were done using Wilcoxon’s signed matched test. Associations were assessed by means of ORs in unconditional logistic regression models.

**Paper III**

Multiple logistic regression analysis was used to test the impact on daily life with regard to frequency, intensity, and duration of TMD symptoms, headaches, and NSP, together with age and education.

The dependent variable; answers on the ADL scale for TMD was dichotomized into those who stated 0 and those who stated ≥1 for the regression analysis. Answers on the ADL scale for headaches and neck or shoulder pain were dichotomized, respectively, into those who stated <4 and to those who stated ≥4, and used as dependent variable in the regression analysis.

In the logistic regression model for ADL related to TMD, answers concerning symptom frequency, intensity, and duration, and age and education were used as independent variables, first, factor by factor, and then, all factors that showed a statistically significant relationship to the dependent variable in the univariate analysis were added into the model in a forward likelihood ratio analysis. In the logistic regression model for ADL related to headaches and neck and shoulder pain the same procedure was applied.
Before the analysis, the independent variables were recoded as follows: The frequency of symptoms was recoded as: 0 = No, never/No, not at present; 1 = Once or twice a month at most; and 2 = Once a week to daily. The duration of each symptom was recoded as 0 = Never had symptoms, 1 = <1 year, and 2 = ≥1 year. The intensity of each symptom was recoded as 0 (= 0 on NRS), 1 (= 1–4 on NRS) and 2 (=5 on NRS). Education was dichotomized into those who had studied nine years at most and those with longer education (senior high school or university). Comparison between age groups for presence of different symptoms in the jaw–face, head, and neck–shoulder region was done with a chi-square test. Ages were grouped in 10-year clusters (21–30, 31–40, 41–50, 51–60, and 61–70) for descriptive reasons.

**Thematic interviews (Paper IV)**

**Data collection**

The selected informants were phoned and an agreement on time and place for the interview was decided. The women could choose to have the interview at one of the public dental clinics after working hours or if they preferred, the interview could be conducted at their home. All women gave their informed consent and were assured anonymity and confidentiality. I conducted all the interviews, using a thematic interview guide covering life history, the Sami heritage, and health and illness experiences and beliefs. The guide was pre-tested in pilot interviews before the study began. The interviews were tape-recorded and took 45–75 minutes. The interviews were fully transcribed verbatim and then cross-checked with the tapes for accuracy. The text files were transferred to a database, Open-Code (ver. 3.3), a computerized tool to sort and classify the data.

**Data analysis**

The analysis was based on grounded theory. The first step in the analysis process is to go through the text, line by line or sentence by sentence, and write down codes, which are characteristics, and capture what is going on in the data. The codes are initially close to the text and may be actual words that the informants use. The next step is to decide which codes are important, then cluster them together and transform them into categories with different levels of abstraction. The categories derived must be relevant and meaningful and describe the phenomenon under study. A category can be described as a concept with which to organize reality. The codes and categories are constantly compared with data collected earlier, so that commonalities and variations can be determined. The data collection ends when the findings are saturated, that is, the categories are solid and
recognizable in all interviews. A major component in GT is the discovery of a core category. The core category is a pattern of behavior that is relevant for the study participants and related to the categories identified. The first coding procedure was performed manually and separately by me and my two supervisors, going through the texts and annotating the transcripts with codes and tentative categories in. Numerous meetings followed, involving comparisons of codes and evolving categories, putting new questions to data, and formulating a core category and theoretical outlines. Discussions continued until consensus on the categorizations was reached.
Table 4. Example of the process of analysis: quotations, codes, subcategories, and categories leading to the core category

<table>
<thead>
<tr>
<th>Quotation</th>
<th>Codes</th>
<th>Sub categories</th>
<th>Categories</th>
<th>Core Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was chewing a caramel and then something happened here on the left side, like it jumped out. I don’t know what happened. And then it swelled up and that's what I've had ever since then. I think it began with this injury with the caramel... that there was an uneven stress and that it affects the entire body.</td>
<td>Chewing</td>
<td>Biting behavior</td>
<td>Triggers</td>
<td>Grin(d) and bear it</td>
</tr>
<tr>
<td></td>
<td>Something happened</td>
<td>Inflicted injury</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Don't know what</td>
<td>Bodily strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ever since</td>
<td>Impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Strain</td>
<td>Musculoskeletal Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No, when I get stressed I bite. I bite and become so focused on what I'm doing so that I'm not aware of what is happening around me. I'm extremely focused on getting done whatever is lying around waiting for me. I bite down and become quiet, until, until I have finished doing most of the job.</td>
<td>Stress</td>
<td>Stress</td>
<td>Strain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bite together</td>
<td>Bite together</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Focused</td>
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<td></td>
<td>Awareness</td>
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<td></td>
<td>Active</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Bite together</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>He [the dentist] examined every which way. He turned and twisted and checked everything and he didn’t find anything wrong. He couldn’t figure what I had. He was downright rude, I think.</td>
<td>Examined from all angles</td>
<td>Ignorance</td>
<td>Distrust</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nothing wrong</td>
<td>Mutual mistrust</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unfriendly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Blame on me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sure there are days when you don’t feel so great, and then I usually think that it’s just my imagination and then you get a second wind. In some way I’ve accepted that you aren’t always at your best.</td>
<td>Bad days</td>
<td>Visions of health</td>
<td>Reconciliation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not feeling fit</td>
<td>Acceptance</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>It’s imagination</td>
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<tr>
<td></td>
<td>Come through</td>
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<tr>
<td></td>
<td>Accepted</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Not always on top</td>
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</tbody>
</table>
Results

Study population

In total, 82% of the women identified themselves as Sami. Six percent stated that they were not quite sure of their affiliation to the Sami population. The majority (63%) of the latter group reported that their uncertainty was because they were not active in reindeer herding or did not speak the Sami language, but their basic family background was nevertheless Sami. Seven percent were married to a Sami. The remaining 30% gave no comments or commented that the question was irrelevant.

Twelve percent of the women did not consider themselves as Sami. The majority of these (53%) stated that their roots were Sami but that they were not living as a Sami or were not viewed as a Sami among other Samis or authorities. Twelve percent of these women were married to a Sami, 24% stated that they were not Sami, but most of them were reindeer owners, and 10% made no comments.

In the total study population of Sami women, 12% reported they were working actively with reindeer herding, and 63% were working outside their homes, twelve percent were retired or had a disability pension, ten percent were studying, and eight percent were unemployed.

The majority of the Sami women (86%) reported that their general state of health was good, whereas 13% reported that their health was not so good, and one percent that it was bad. Almost one of four reported that they had a disease that was under medical care, and 29% had medicine prescribed by physicians on a regular basis.

Symptoms indicative of TMD

The prevalence of ongoing symptoms indicative of TMD varied between 8% and 32%, depending on the criteria used to determine frequency and intensity. The prevalence of ongoing symptoms indicative of TMD was 32%, of which approximately half (17%) were symptoms reported at a frequency of at least once a week; this was reduced by half again (8%) when only those were included who also stated that their symptoms intensity level was at 5 or more on the NRS. When the criterion of impact on daily life, registering more than one on the NRS was added in, the prevalence was further reduced to 6% (Figure 3).
Tiredness in the jaws and TMJ sounds were the most commonly reported symptoms indicative of TMD, each being reported by approximately 20% of the women. Pain in the jaw–face region was reported by 7%. The mean stated intensity of ongoing TMD symptoms on the NRS varied between 3.3 (SD 2.8) and 4.7 (SD 3.1). The lowest mean intensity was stated for TMJ sounds and the highest for TMJ locking. The majority (74–96%) reported that their symptoms had been present for more than one year.

The most common frequently occurring symptom indicative of TMD was TMJ sounds (12%). Pain in the jaw–face region, once a week or more often was reported by 3%. The lowest mean intensity was stated for TMJ sounds (3.9, SD 3.1) and the highest for pain in the jaws (5.8, SD 2.5). The majority (67–98%) reported that their frequent symptoms had been present for more than one year. The highest prevalence of frequent (≥ once a week), longstanding (≥ 1 year) and intense symptoms (≥ 5 on the NRS) indicative of TMD was found for TMJ sounds (5%) and tiredness in the jaws (3%).

The prevalence of frequent symptoms indicative of TMD was significantly higher among younger than among older women. The odds ratio of reporting frequent symptoms of TMD in the 21–30 as compared to the 61-70-year-old age group was 5.8. The prevalence of frequent, longstanding, and intense symptoms of TMD showed a gradually declining trend with age, but the difference between age groups was not statistically significant (Figure 4).
RESULTS

Headaches and neck–shoulder pain

More than half of the Sami women reported headaches (61%) and NSP (56%). When only frequently occurring symptoms were considered, the prevalence of headaches was reduced to 19%, and of NSP to 30%. Eleven percent reported frequent and intense headaches, and 21% frequent and intense NSP. The mean stated intensity level was 6 for both frequent headaches and frequent NSP. More than 80% reported that these symptoms had been present for more than one year. The prevalence of longstanding, intense headaches was significantly higher in the younger age groups than among the older. The prevalence of frequent headaches showed a gradually significantly declining trend with age. The pattern of frequent NSP showed a gradual increase up to the age of 60, but the difference in relation to age groups was significant only for longstanding, intense neck pain (Figure 4).

![Figure 4](image.png)

**Figure 4.** Percentage distribution of frequent (once a week or more often) and grievous symptoms of TMD, headache, and NSP, respectively, in five age groups of women in a Sami population (21–30 yr, n = 82; 31–40 yr, n = 116; 41–50 yr, n = 117; 51–60 yr, n = 105; 61–70 yr, n = 67). Grievous denotes that symptoms occurred at least once a week, with a reported severity level of 5 or more on an 11-point numerical rating scale (NRS) and were of at least one-year's duration.

Disability related to symptoms indicative of TMD

Of those 142 women with ongoing symptoms indicative of TMD and stating a related impairment of their ADL on an NRS, 57% reported that the symptoms affected their ADL to some degree and 19% stated a value of 5 or higher on the NRS. When calculated based on the total sample of Sami women, 6% thus reported a substantial effect on their ADL from symptoms indicative of TMD. A total of 8% (n=39) reported longstanding, frequent,
intense symptoms indicative of TMD and of these, 77% (n=30) stated that their symptoms interfered with daily life. All women who reported frequent jaw pain stated their ADL was negatively affected. The majority of those who reported no negative interference at all were those with frequent longstanding TMJ sounds.

In the multivariate analysis including all independent variables that were statistically significant for an effect on ADL related to TMD in univariate analyses, low education level, reported intensity level of impaired jaw opening, reported intensity level of neck pain, and duration of jaw pain remained in the model as factors significantly related to the women’s reported effect on ADL related to symptoms indicative of TMD (Figure 5).

**Disability related to headaches and neck–shoulder pain**

Almost half of the study population reported that headaches (47%) or NSP (48%) to some degree disturbed their daily activities. The interference was scored 5 or higher among 23% for both headaches and NSP. Twenty-one percent reported longstanding, frequent and intense pain in the neck and/or shoulder region, and 97% of these women stated that the pain had a negative impact on their ADL. Eleven percent reported longstanding, frequent, and intense headaches, and all of these stated that their headaches negatively affected daily life.

In the multivariate forward logistic regression model the stated intensity level of headaches and frequency of tiredness in the jaws remained as factors significantly related to the women’s statements of the effect of headaches on ADL.

In the multivariate forward logistic regression model stated intensity level of pain in the shoulders, stated intensity level of tiredness in the jaws, and stated intensity level of neck pain were factors that significantly related to the women’s statement of the effect of NSP on ADL (Figure 5).
RESULTS

Figure 5. The black pies show the percentage of those who reported that their symptoms to some degree disturbed their daily life activities. The bars show, respectively, the percentage distribution of the degree of interference with daily life stated on the NRS in relation to the symptoms. Black bars indicate cases and white bars indicate controls used as dependent variables in the regression analysis. Odds ratio (OR) and 95% confidence interval (CI) presented for the significant factors that remained explanatory in multiple logistic regression analysis.

Co-morbidities

A reported impaired general state of health was significantly related to ongoing TMD symptoms (OR 2.1, 95% CI 1.2–3.5), ongoing frequent TMD symptoms (OR 2.7, 95% CI 1.5–4.8), and longstanding, frequent, and intense symptoms indicative of TMD (OR 2.8, 95% CI 1.3–6.0).

Statistically significant associations between frequent symptoms indicative of TMD and frequent headaches, between frequent symptoms indicative of
TMD and frequent neck–shoulder pain, and between frequent headaches and frequent neck–shoulder pain were found.

These associations were similar when the criteria of longstanding and intense were added. Approximately 50% of those with frequent and more intense symptoms indicative of TMD as well as of those with frequent and more intense headaches also had frequent symptoms in the neck–shoulder region (Figure 6).

**Figure 6:** Relationship between women who reported longstanding, frequent symptoms indicative of TMD, headaches and neck–shoulder pain (NSP) with an intensity level of 5 to 10 on an 11-point numerical rating scale (NRS). Odds ratio (OR) and 95% confidence interval of the relationship between cases with the symptoms.

**Case–control study**

The mean age of the clinically examined study population was 48.7 years (SD 13.1). The positive predictive value of having signs and frequent symptoms indicative of TMD was 0.82; the negative predictive value was 0.87 at the two-year follow-up. An annual incidence rate of TMD was 6.5% among controls. Cases had significantly higher odds ratios of reporting impaired general health, taking prescribed medication, and being aware of tooth clenching and tongue pressing than the controls. A diagnosis in accordance with the RDC/TMD classification system was established in 59% of cases. Symptomatic TMJ disc displacement was diagnosed in 46% of cases compared to diagnosis in 7% of the controls (P < 0.001). Myofascial pain was diagnosed in 40% of cases as compared to 2% of controls (P < 0.001). Diagnoses of TMJ arthralgia and TMJ arthrosis were established in 5% and 9%, respectively, of cases, but in none of the controls; the difference between cases and controls was not statistically significant. The distribution of symptoms (Ai) and clinical signs (Di) of dysfunction is presented in Figure 7. In total, 91% of cases had signs of dysfunction compared to 37% of controls.
RESULTS

Figure 7. Percentage distribution of frequent (≥ once a week) symptoms (A) and signs of TMD (B) among controls (white bars) and TMD cases (black bars) in Sami women. A. Ai 0 denotes no symptoms, Ai I denotes mild symptoms, and Ai II denotes severe symptoms of dysfunction. B. Di 0 denotes no signs, Di I denotes mild signs, Di II denotes moderate signs, and Di III denotes severe signs of dysfunction.

The following clinical observations were made among cases and controls:

**Dental occlusion**

- Two subjects, one in each group, were edentulous.
- The mean number of teeth was 25.2 (SD 7.2) with no statistically significant difference between cases and controls.
- No statistically significant difference was found between cases and controls in classifications of morphologic occlusion (neutroclusion 72%, distocclusion 27%, mesiocclusion 1.5%, deep bite 16%, open bite 3%, edge-to-edge bite 8%, cross bite 8%, and scissors bite 3%).
- No statistically significant difference was found between cases and controls for contact patterns in centric relation (unilateral contact in 57%), or slide in centric or contact patterns in eccentric positions.
- Cases had fewer contacting pair of teeth in centric occlusion (mean 8.2, SD 2.9) than controls (mean 9.8, SD 2.8) (P = 0.034).
- There was no significant difference between cases and controls in the distribution of supporting occlusal zones according to the Eichner index.
Degree of tooth wear

- Forty-three percent of the cases were registered with considerable tooth wear and with obvious change of anatomical tooth form (Mike or Tango) compared to 36% of controls. No significant differences were found between cases and controls.

Mandibular mobility

- No statistically significant difference was found between cases and controls for mandibular mobility. The mean maximal jaw opening capacity was 48.4 mm (SD 6.5), the mean laterotrusion to the right side was 9.1 mm (SD 2.5), the mean laterotrusion to the left side was 9.0 mm (SD 2.7), and the mean maximal protrusion was 8.7 mm (SD 2.2).

TMJ signs

- Temporomandibular joint sounds were registered in 50% of cases and 9% of controls (P <0.001).
- Tenderness to palpation over the TMJ (lateral and/or posterior) was registered in 4.5% of cases and 2.2% of controls, with no statistically significant difference between the two groups.
- Pain was elicited from the TMJ region in 26% of the cases and in none of the controls (P =0.002).

Muscle signs

- Tenderness to palpation over jaw muscle sites was registered in 68% of cases and 20% of controls (P <0.001).
- Forty-five percent of cases developed symptoms during a 30-second clenching task compared to 15% of controls (P =0.007).

Perception thresholds

- All those included in the study population had similar tactile perception thresholds at all tested regions of the face, as determined with von Frey filaments.

BMI

- The cases had a statistically significantly (P =0.027) higher body mass index (28.2) than did the controls (25.4).
Thematic interviews

The core category derived from the categories was “Grin(d) and bear it.” It summarizes the informants’ various ways and stages of processing and handling the interacting categories that emerged in the analysis: (1) triggers, (2) strains, (3) distrust, and (4) reconciliation with pain and/or difficulties in life (Figure 8).

For women with TMD the core category described their awareness of regular tooth-clenching behavior whenever they were in pain or stressed. Informants without TMD used the same expression, but more as a metaphor for a strategy for handling difficulties in life.

Women with TMD expressed both similar and divergent understandings and experiences of related impairments. The women without TMD contributed foremost with their thoughts regarding factors that helped them to handle strains, reconcile, and stay healthy. Women with and without TMD seemed to cope differently with life situations. The healthy women handled difficulties in life by leaving bad experiences behind; they were looking forward and striving to get on with life, despite any difficulties. To succeed in this strategy, they relied heavily on support from family and friends. The women with persistent symptoms of TMD described a life situation characterized by a limited social network, loneliness, and a feeling of being an outsider, off the labor market and also outside the health care service. They did not know where to find help for their symptoms. They also expressed feeling unsafe and uneasy. All informants expressed both negative and positive experiences of the Sami heritage.
The following section presents the four categories that emerged from the analysis.

**Triggers**

This category involves reflections and possible etiological explanations of why and how pain symptoms in the jaws might evolve. These explanations were varying; the onset was sometimes related to a sudden local injury, in the orofacial area, in the neck, or elsewhere. Mostly, however, the jaw dysfunction had evolved insidiously.

Co-morbidities were described between TMD symptoms and symptoms from the neck and shoulder region. Diseases, such as sinusitis, muscle diseases, rheumatic diseases, asthma, glaucoma, and hypertension were also reported.

“Well, I think that’s because of my muscular disease. Oh yes, there’s a connection, all right. And that I tense up when get stressed, and then my jaw gets tight.”

One woman related her jaw problem to an ankle fracture a long time ago, which she believed had changed her body posture and thereby caused TMD.

“It has developed very gradually, but I believe a lot of the damage happened that time in ’87 when I hurt myself—that I put on weight and got this postural imbalance. I don’t know if that’s a part of it. That my body has gone crooked.”

One woman related her problems to a virus infection in the 8th cranial nerve. Another woman thought heredity might be a cause, as her mother had arthritis and her father had rheumatic disease.

“So you wonder, is it something hereditary is it something in our genes that caused it, or just what is it? Because the fact is that of the five of us siblings, none of us is really healthy. Everyone has pain in some joint or muscle.”

Some women with TMD linked their pain to dental treatments, such as a tooth extraction or a dental prosthesis. One woman had to clench the jaws together to keep her dentures in place. Bruxism, such as, tooth clenching and tooth grinding, were common explanations suggested by the women with TMD.
The women without TMD offered possible reasons for why they had managed to avoid having TMD; for example they had few medical problems, and no muscle tenderness or hereditary muscle problems. The impact of financial or other personal problems on health was also mentioned:

“Maybe it’s because I’m not stressed. I don’t lie around, gnashing my teeth.... I think you develop pain if you have this kind of stress, money worries and one thing after the other. In the end it just gets to be too much. I don’t have anything like that.”

They also more often described awareness of ergonomic relationships to musculoskeletal disorders.

...and at work I think about lifting properly, so then it doesn’t happen, either.

Physical activities during childhood, protecting them from pain and dysfunction disorders were also considered.

“And it may also be because when we were little, we also had to work a lot. Carry in wood and carry water and work hard outdoors.... That you’ve really built up your muscles. That could be it. And we were outdoors a lot and went skiing and sledding. We were active. Really active. We were rarely indoors. I don’t know if it has to do with that.”

Strains

This category involves behaviors of biting/clenching/holding teeth together, mental strain, bodily strain, and stress. A relationship between stressful situations and tensions or pain in the body, foremost from the jaw-face, head, and neck region, but also in other locations was described. The women mentioned awareness of biting, clenching, or holding their teeth together in specific life situations. Some reported these activities as a part of their normal everyday behavior, a momentary event; others, as an ongoing habit:

“Yes, I’m always sitting around with my teeth clenched. You see, I grind my teeth a lot, you know. I feel like I wake up with it. I can wake up with the worst headache in the world, and my jaw is stiff. And it’s because I’ve clenched my teeth, quite simply.”

“When I’m lying down reading, I lie there and clench my teeth. I sometimes notice then that my muscles are getting tired.”
Some women had common experiences of difficulties in early life and recalled various stressful situations, for example early separations from their parents, as they were sent to nomadic schools—special schools for Sami children from the age of seven, and other traumatic events such as teasing and harassment by other school children.

“When you got to school, you didn’t know anyone. There was one person who became my guardian angel. When she graduated, you could say that all hell broke loose. I was bullied then, and it wasn’t much fun.”

Feelings of having been treated as outsiders by the majority group, and experiences of marginalization of the Sami society under Swedish laws were also expressed. Many had been forbidden to speak their mother tongue and had therefore lost their Sami language, one important marker of ethnic affiliation. Situations where they had to defend the Sami people and culture, and sometimes had chosen to hide their Sami origin, were also described.

**Distrust**

This category involves feelings of mistrust and distrust regarding the women’s contacts with medical and/or dental health services. They expressed a belief that physicians and dentists suspected that their main objective was to be on sick leave or to have other secondary gains. They shared negative experiences of the general health services, and also mentioned inaccessibility.

“And he asked if I wanted to go on sick leave. I got angry at him. I said that I don’t run here because I want to go on sick leave; I come because I want to get help. And, yes, we discussed it—in the end I felt that he did not believe anything I said, so I walked away. I said that I have no reason to be here if you don’t believe me, and so I left. Yeah, he was really stupid, in my opinion.”

Some women expressed mistrust of the care providers’ competence and ability to manage their problems:

“What kind of a doctor could there be who would understand this? I’ve looked high and low.”

Mistrust towards treatment received was also described. Many reported that they had tried oral splints or adjustments of the occlusion. Their common
experiences of these treatments were that they had no major effect on symptoms.

“I’ve had oral splints. I’ve tried several of them, but I don’t know that I’ve gotten any better.

A few women expressed passiveness regarding things they needed to manage, for example, physical activities, work ability, and household work. They seemed to be stuck within the pain condition, which was keeping them back from enacting changes in their lives.”

“I wish it would just disappear. That I could move my body more without feeling absolutely numb with pain. Do something at home without feeling sudden pain, like, “Oops, can’t do that now”... Yeah... If only I’d been spared that part, I could have gotten through anything.”

Reconciliation

This category describes the Sami women’s wish, intention, and strength to “bear it” and move on with life, despite difficulties.

The women related to their Sami heritage with pride and appreciation for the possibility of gaining health: a free, unrestricted, and sound life “up in the mountains.” To be included and accepted in the Sami group was also of great importance.

“They like, I’ve like felt that when I’ve been having a really rough time, I’ve gone out into nature. Gotten connected—so I’ve meditated a great deal, gone to yoga class and stuff like that. And it’s a way for me to feel I can, you know, keep on going with this. That I need to get out into the wilderness, so my kids can say, “Mom, here’s a place where you can meditate.”

The women described different physical activities undertaken to improve their well-being. The majority also utilized care from different professions, such as physicians, physiotherapists, and dental surgeons, and also from alternative medicine therapists, in their search for alleviation.

Self-treatments were a part of the women’s strategy to find their own way to manage daily life. Over-the-counter medicine, stretching, and massage were common examples mentioned.
“Yes, I often have a headache and feel stiff in the jaw. I try to sit down somewhere then and massage myself. And then I feel after a while it goes away and my muscles relax—and they’re always tense.”

“I try now—I take an analgesic and try to massage the back of my head a little. It usually helps. If my head and my jaw are really hurting I’ll take a warm shower, and that makes me feel better.”

Some women had reached a point of acceptance and tried to make the best of their situation:

“In some way I’ve accepted that you aren’t always at your best. You can’t always feel so great. It’s just sometimes like this.”

Social networks with others in the same situation were important for managing their longstanding TMD problems.

“Then I meet up with my fibromyalgia buddies, and that’s so nice. Because we understand each other. They’re not any healthier than I am—some of them are actually worse off some days—and we cheer each other up and encourage each other.”

The healthy women seemed to handle difficulties in life by leaving bad experiences behind, looking forward, and striving to get on with their lives, despite difficulties. To succeed in this strategy they relied heavily on support from family and friends. They tended to have a more conciliatory approach to solving problems and handling shortcomings:

“I try to manage to get the (important) things done that I have to do. In other words, I know that maybe I planned so I would have time to do more, but then I don’t. It really doesn’t matter. If you don’t have time, you don’t have time.”

Good health was mainly described and perceived by the women in terms of ability to work and having energy left for leisure time.

“If you don’t have the strength for physical activities, you don’t have good health and quality of life.”

Other important factors related to good health were feelings of safety, freedom, good mental health, stable finances, and a healthy family.
Discussion

Main findings

Signs and symptoms indicative of temporomandibular disorders, headaches and neck–shoulder pain, were common conditions in Sami women living in the Arctic region of Sweden. The prevalence of these conditions was essentially similar to those reported in other population studies on women. It should be emphasized that any reported prevalence of TMD symptoms strongly depends on the criteria used for frequency and intensity. There was a tendency of higher prevalence of headaches and TMD in the younger compared to the older Sami women. This finding is in line with studies on the general population in Västerbotten, Sweden (Yekkalam and Wänman 2014a), and in Jönköping, Sweden (Anastassaki and Magnusson 2004). The study also indicates that for quite a large part of the Sami women, the activities of daily living were negatively influenced by the frequency, intensity, and duration of pain in the jaw–face region together with impaired jaw opening and co-morbid symptoms of pain in the neck. The results are in agreement with those from a systematic review that demonstrated that OHRQoL of life was negatively affected among TMD patients (Dahlström and Carlsson 2010). Epidemiological studies have seldom found that variations in the dental occlusion have had a major impact on prevalence of TMD (Carlsson 2010, Türp and Schindler 2012). This study was no exception, since occlusion did not clearly distinguish whether a Sami woman was a TMD case or not, in the cross-sectional analysis. TMD cases reported impaired general state of health and awareness of parafunctions more frequently than controls.

In the qualitative part of the study the narratives from Sami women with more severe and longstanding symptoms of TMD relayed that they perceived that the jaw often felt strained. Although the informants (TMD cases) were strategically selected based on their TMD signs and symptoms all of these also had other symptoms such as headaches, NSP and tinnitus. The Sami women shared common thoughts and experiences about factors that might trigger and perpetuate TMD symptoms, headaches, and NSP. In the narratives they expressed distrust, one on hand, in the capabilities of the health care providers to handle symptoms of pain and dysfunction, but also reconciliation experiences, on the other, indicating that these women’s needs had not been met by the dental and health care system.

Study population

Epidemiology as a scientific method focuses on the incidence, prevalence and determinants of disease in human populations. Patterns of illness in the population are examined to try to gain knowledge about why certain
individuals develop a specific disease, whereas others do not (Greenberg et al. 2001).

The Sami population may from certain perspectives be viewed as a fairly homogenous group, with regard to ethnicity, culture, traditions, resources, language, geographic living area, and to some extent, also genetics. As such, they may help to add knowledge about development and determinants of specific diseases. The Sami society of today can be regarded as integrated into the Swedish society. According to the thesis by Andrea Amft from 2004, marriage within the Sami society is not longer a necessity. She also reported that Sami women traditionally take more responsibility than men for care of children and household chores, as in most other cultures. Responsibility for the products of the reindeer herding enterprise, such as food and materials for sewing clothes, has traditionally also been among the Sami women’s duties (Amft 2000). Only the oldest women in this population had experience of a more traditional, nomadic way of living.

The feeling of considering themselves included in the Sami society was addressed in one question. Despite the study population having been defined according to the Sami Parliament’s criteria, almost one out of five expressed doubts of being regarded as a Sami. This result may reflect that having heredity in the Sami culture is not enough, if they are not viewed as a Sami by other Samis or authorities. Identity is created through discourse, and not automatically transferred. Although a person is born Sami, but it is the person’s upbringing that determinates whether the person becomes a Sami. Sami women have to subordinate themselves to be a “genuine” Sami, and if a woman were to take a political stand as both a Sami and a woman, she might risk being defined as an outsider in relation to the ethnic group (Amft 2000). Some women in this study had difficulties in identifying themselves as Sami since their membership in the electoral register was related to matrimony. They were nevertheless a part of the Sami society and culture. Three percent of the women had a reindeer mark, were registered in the Swedish Board of Agriculture, and stated that they were not Sami. In our analyses, we did not find that there were any significant differences in the distribution of answers between those who were active in reindeer herding and not, and between those who stated that they were Sami and the rest of the sample. The study population included in this thesis may be considered as a fairly homogeneous sample in the sense that they are all women who share the Sami heritage and are living in the Swedish Arctic region.

The strategic choice to exclusively study women was based on the indications that TMD symptoms, headaches, and neck–shoulder pain are more common in women (Bovim et al. 1994, LeResche 1997a, Jensen 1999,), and that longstanding TMD pain and dysfunction are more commonly observed in women than in men (Wänman 1996, Kuttila et al. 1998, Rantala et al. 2003, Goncalves et al. 2010). Longitudinal studies of TMD have shown a fairly
DISCUSSION

consistent pattern of predominantly transient symptoms of pain and dysfunction with time (Könönen and Nyström 1993, Kitai et al. 1997, Magnusson et al. 2000, Nilsson et al. 2007). However, in a 10-year prospective study, women were at higher risk of reporting longstanding symptoms, even though significant fluctuations in TMD symptoms occurred over the period (Wänman 1996). There may be unknown factors involved in the maintenance of symptoms that relate to the female gender. Several hypotheses regarding this issue have been proposed, including psychosocial factors (LeResche 1997a, Dao and LeResche 2000, Rantala et al. 2003) and sex hormones (LeResche 1997b, Warren and Fried 2001, Cairns and Gazerani 2009, Cairns 2010). The role of genetic variation in relation to development of TMD is currently addressed in a large prospective research project-OPPERA (Smith et al. 2013). Several factors may thus be related to TMD pain, but no conclusive knowledge has yet been reached. These findings were also reasons for studying a fairly well-defined sample of Sami women from different perspectives.

Since symptoms indicative of TMD, headaches, and NSP have fairly high prevalence, the size of the study population was considered acceptable. Dropouts complicate the assumptions and may jeopardize the study results. In the questionnaire study the dropout rate was approximately one out of three. Since the dropout analysis did not indicate any systematic errors related to presence of the symptoms in focus, the study results could be considered reliable. The risk of sampling error was small since all available individuals from the Sami register were included. The register on the other hand represents a clearly biased group in relation to the total Swedish population. The most common reason given for declining to participate was “on principle.” Discrimination was also mentioned as a reason. Stigmatization can occur among Indigenous Peoples, and discrimination of Samis is an ongoing debate (DO2008:1, DO2008:2, Ledman 2012a, Omma 2013).

Methodological considerations

Questionnaire
The balance between the number of questions included in a questionnaire and the expected number of participants willing to take the time to answers all the questions in population-based studies influenced the design of the questionnaire. It was structured around defined symptoms and their occurrence, intensity and duration. A question may address a condition’s occurrence on a lifetime, yearly, monthly, weekly, or daily basis. It is obvious that the outcome will be influenced by the wordings used. It has previously been reported that the reliability of answers to questions regarding symptoms of TMD increases when a frequency of once a week or more often is used as the time frame and probably also the “clinical relevance” increase when this time frame is used as an inclusion criterion (Nydel et al. 1994, Wahlund et al. 1998, List et al. 1999). In this study the questions were
constructed so the prevalence could be calculated for different time frames in order to compare the results with previous studies and to identify women with more frequent, intense, longstanding, and disabling symptoms for the subsequent thematic interviews.

To assess the intensity of symptoms as well as the impairment related to TMD symptoms, headaches, and neck–shoulder pain the NRS was used. Rating scales are commonly used to capture pain intensity and shown to have an acceptable reliability (List and Helkimo 1995, Conti et al. 2001, Williamson and Hoggart 2005), as well as having the advantage of also being easy for participants to understand (Williams et al. 2000). Disadvantages of a rating scale are that the individual’s interpretation of the scale may differ, and thus, inter-individual comparisons are scarce. The scales can also be criticized for being one-dimensional. The validity of the NRS for capturing the severity of impact on daily life is not known. In the analysis of TMD the scale was dichotomized into those who stated no interference at all and the remaining women which we considered reasonable in relation to the analysis. The dependent variable was thus composed of an approximately equal number of those with and without impairment related to TMD symptoms. In the corresponding analyses of impairment related to headaches and NSP, the dichotomizing split was based on the distribution of the response, also creating an approximately equal numerical size in both groups. In the graded chronic pain scale (Von Korff et al. 1992) the pain score is dichotomized into the lower (<5) and higher (≥5) levels. The split in this sample may thus be interpreted as between those with a lower and a higher impairment related to headaches and neck–shoulder pain, respectively.

Different classification systems were used to cluster the women’s TMD–related symptoms, using the RDC/TMD criteria to establish a diagnosis (Dworkin and LeResche 1992), and the Ai and Di for severity of dysfunction. Both systems are well-established and internationally used classification systems. The Helkimo indices have been criticized (van der Weele and Dibbets 1987) and the RDC/TMD recently adjusted (Schiffman et al. 2014). The Ai captures presence of symptoms indicative of TMD. Based on the results from the present study, the index division in severity may be questioned. The severity of a condition is a subjective experience, and the subjects’ reports of symptoms’ intensity levels and their affect on daily life expressed on the NRS were similar for Ai 1 (mild symptoms) and Ai 2 (severe symptoms), as shown in figure 3. In support of the division used was the observation that most of those who reported no affect on daily life were those with TMJ sounds. The RDC/TMD diagnostic system may also be criticized, since it has its main focus on pain conditions, which is too limitative for the disorder. In this study population TMD pain had certainly affected the women’s ADL, but so had symptoms of dysfunction.
**Case–control study**

The design of the case–control study was to compare individuals with symptoms indicative of TMD and those without symptoms, as identified by the questionnaire. The study has several strengths: cases and controls were selected from the same population, and thus had the same sex, ethnicity, and culture. Cases were identified based on severity of their symptoms and not on their status as consulting patients or as referrals. Twice as many controls as cases were included, and they were age-matched. The selection also focused on the extremes at each end of a normal distribution, with regard to severity of symptoms in the jaw–face region. The examiner (AW) was an experienced TMD specialist, and throughout the study was kept blinded to the women’s affiliation. Since two years passed between the first and second examinations, the identified cases really could be defined as severe cases with persistent TMD symptoms. Only those who subjectively considered themselves as Sami were included, because one of the themes of the subsequent, planned, thematic interview study was the life experience of being a Sami woman.

Because of relatively few cases twice as many controls were selected. Nothing, however, indicates that dropout was related to changes in TMD symptoms. The main reason for dropping out was that they could not be reached because they had moved away from the included municipalities. There were no statistically significant differences in answers to the first questionnaire between the participating women and those who were not accessible. Having a small number of participants increases the risk of making a type-2 error in data interpretation and accepting a null hypothesis, even though it is false. The distributions of most clinical variables examined in the cases and controls were, however, quite similar, so even a significant increase in the number of cases and controls would hardly have changed the interpretation of the results.

**Interview study**

The qualitative research approach was used to get insights into the women’s experiences and beliefs and to generate hypotheses of factors that might influence the development of longstanding TMD. The informants were strategically selected from the epidemiological sample, which may increase transferability. The selection of informants was based on their experience of having longstanding, severe TMD symptoms, or having no experience of TMD, and being approximately the same ages. The women who were included had consequently varying experiences relating to education level, family status, and working conditions, as a reflection of their different social living conditions. No Sami woman in the older ages was included, since there was no one available with severe symptoms. This finding is interesting by
itself and may warrant further qualitative studies addressing specifically women after retirement.

Grounded theory was chosen, as it is an established method used to explore complex phenomena and patient experiences in the health sector. The data collection ended when the categories were considered solid and recognizable in the interviews. To enhance credibility, triangulation, peer debriefing, and negative case analysis (Dahlgren et al. 2004) were used. The three of us researchers, separately performed the coding procedure, and meetings and discussions ensued until consensus had been reached. We all had different backgrounds, pre-understandings, experiences, and perspectives, which were considered an advantage, as it contributed to triangulation in the analysis procedure. I have, as a native Sami woman myself, an “insider perspective,” used as knowledge. The other two investigators provided the perspectives of a male dentist specialized in TMD (AW) and a female general practitioner (EEJ) with specific interest in chronic pain conditions. Preliminary findings were discussed with colleagues outside the process for inputs and comments, assigned to peer debriefing. Negative cases were included as references, not for direct comparisons, but to distinguish general life experiences among Sami women and those more specific to TMD cases.

**Ethical considerations**

The study was approved by the Regional Ethical Review Board at Umeå University, Sweden. As the ethical review in Sweden does not specifically consider Sami perspectives, I have chosen to relate to ethics more thoroughly than is required by Swedish law (SFS2003:460), as discussed by Ledman (Ledman 2012a). In practice, this implies that the study also has been carried out in contact with the Sami Parliament in Sweden. They approved the use of the electoral register and have also supported the study with grants. The results have been reported to the Sami Parliament for those papers they have supported. The results have also been reported in public, in conferences both within the field and also on a conference with Sami context. The study received attention in Sami media when it started, and my intention is also to report the final results in a more popular form. From these perspectives the research process has been transparent, and the Sami society has been given the opportunity to take part in this process. This approach is in line with what is recommended within international standards for indigenous research (Ledman 2012a, Smith 2012).

In studies of a specific group of people, as in this case, a specific gender and an ethnic minority, stigmatization is a potential risk, as both the individual and the group may believe they are being accused. The risk in this case was considered low. As a native Sami, I might have increased the participants’ confidence. Even as an insider, one may have an outsider perspective (Åhren 2008). It is, however, more likely that the insider brings more familiarity
with the prevailing norms and values and can use this pre-understanding in all phases of the research process. An example of being an insider for me was that during the interviews an informant sometimes did not explain deeply her experiences, instead commenting, “...but you know how it is—you are a Sami woman yourself.”

Epidemiological studies on the Sami population in Sweden were, at the beginning of the year 2000 when this study was initiated, limited. Knowledge about the health situation and living conditions has since increased and is still increasing and required. In other countries with Indigenous peoples, such as Canada, Australia, United States and New Zealand, certain ethic guidelines for indigenous research have been developed. These have been designed according to the Indigenous people’s own values, standard, and requirements (Ledman 2012a). Such ethical guidelines are not available in Sweden, but are warranted (Nilsson LM 2012). As the indigenous researcher Linda Tuhidai Smith wrote in her book, Decolonizing Methodologies, “research is probably one of the dirtiest words in the indigenous world’s vocabulary” (Smith 2012). I also experienced some skepticism, especially when the questionnaires were sent out. Some came back with comments about the negative feeling of being selected through a register. They mentioned the dark era in Swedish history with the race biology studies, on the Sami people, who were considered a lower status race during that time (Ledman 2012b, Lundmark 2007). The researcher may be presumed to represent all the research that has conducted on the Sami people, including research perceived as negative (Ledman 2012a). This is a further aspect to have in mind when entering into a project with indigenous themes.

Ethical risk is always to be considered in research of humans. The study was conducted following the ethical principles for medical research involving human subjects according to the World Medical Association Declaration of Helsinki and the basic ethical principles in human research in accordance with the International guidelines for ethical review of epidemiological studies. The principle of respect for persons, meaning for their autonomy and their capacity for self-determination has been relevant throughout the study. The women decided by themselves to first participate in the questionnaire. For the follow-up study they once again decided to participate, and also for the subsequent interview. They were informed during the follow-up (clinical examination) that they might be invited to an interview. All of them gave their consent to be contacted by phoned and asked for their agreement, and they could also choose to decline to participate at that occasion. It has been my intention to give information as much as possible about the study aims during the data collection process. I
believe that it was one of the reasons why all of them whom I met in clinical settings agreed to be invited for an interview. All the participants were informed orally and in writing about the aims. They were all assured confidentiality and the opportunity to withdraw from the study anytime without having to specify reasons for leaving. This promotes freedom of choice. The study was thus conducted with respect for the right of informed consent. A balance between benefit and harm must always be considered in planning process of the research process. The benefit of this study was considered at the individual level, that those with longstanding pain symptoms could have the opportunity to obtain diagnosis, advice and assistance. On group level possible factors of importance within the group could be identified and lead to proposals for preventive measures. On community level, knowledge of factors important for the development of longstanding TMD is still lacking, and the study may generate increased knowledge in this area. The principle of beneficence means that the expected benefits of the research should be larger than the harms (non-maleficence). In this study, a possible harm could be pain experienced by women during the clinical examination. On the other hand, those participants also could get some benefits in the form of advice for pain relief. In epidemiological studies, particularly in clinical examinations, a sudden unexpected and undesired diagnosis can be found. In this study, in the field of TMD, however, no fatal diseases were expected. A benefit can instead be that the participant was advised to contact her regular dentist or was referred to a specialist in TMD, providing further assessments. The principle of justice has been applied when it has been applicable. The women with pain might had been more vulnerable than the women without pain; all were been treated equally. Transportation costs were supported, so also those who had a longer distance to the examination had the same chance to participate without incurring any costs. There is also a potential risk of the participants feeling subordinate to the researcher. It is my belief that as a native Sami woman myself, I reduced that risk.

All data have been treated confidentially. Questionnaires and interviews were done anonymously and stored, locked up, in a location separate from the code keys. Even though the population was spread between two different communities and areas within the communities (for example, Karesuando), the Sami population have close internal contacts; many are even relatives. No information regarding geographic area was presented, so it would not be possible to identify specific individuals from the interviews. All quantitative data were given serial numbers, which were kept away from personal identification data. The analyses were done at group level, and the participants were remained anonymous throughout the analyses, with the results being presented only at group levels.
Qualitative methodology is regarded as less threatening on an individual level because of the close interactions between the researcher and the informant. It has also been suggested that the methodology empowers people through their active participation in the process (Dahlgren et al. 2004). In the qualitative study, the participants were informed that researchers other than the interviewer were also going to work with the text files. Confidentiality was assured. Private data such as name and so on were kept away from the text files and would not be reported. The audio files were coded and locked away. The key code linking personal identification to a given code number was stored elsewhere. The ethical risks of being a participant in an interview study may include the interviewer getting too close to their life experiences, which may result in stress and fear about the questions asked. This risk was considered as small, since the women were informed about the topics in the beginning of the interview and told that they could choose not to answer the questions if they felt that they did not want to, without offering any explanations. The participants may also start to reflect up on well-being and potential stress events, which may lead to improved self-efficacy. It can be a benefit that someone takes time to listen to their stories.

**Temporomandibular disorders**

*Prevalence*

The prevalence of symptoms indicative of TMD was lower among the Sami women than the prevalence observed in a Sami population examined in the early 1970s. These Skolt and Inari Lapps were at that time more or less uninfluenced by other cultures due to isolation and a high degree of marriage within their society. Their economical standard was low and living conditions simple. They also had a bad dental status but their general health was otherwise good (Helkimo 1974a). The prevalence among the Sami women in this study was close to a median value of symptoms based on several population based studies (Carlsson 1984, Salonen et al. 1990, De Kanter et al. 1993, Rantala et al. 2003.), which, on the other hand, were based on both men and women. In comparison to a survey in Västerbotten in 2002 (Yekkalam and Wänman 2014a) the prevalence of frequent symptoms, as well as the age distribution with higher prevalence in the younger as compared to the older women was similar, except that the peak of prevalence observed in the 50-year-old women in Västerbotten was not obvious in the Sami women. A similar age peak was reported based on a TMD patient sample (Manfredini et al. 2010a). The different prevalence figures related to symptoms indicative of TMD depending on the symptoms reported frequency, stated intensity, and interference with daily living may imply that for most individuals in the general population symptoms of TMD are of low
or inconsistent frequency, or low and manageable intensity. Most individuals thus seem to cope with these symptoms and do not demand treatment. The 6–8% who reported more significant symptoms of TMD resembled estimated treatment needs in the adult population (Agerberg and Carlsson 1975, Locker 1988, Alanen et al. 1997, Kuttilla et al. 1998, Carlsson 1999). The results therefore add understanding to why previous fairly high prevalence figures reported in epidemiological studies never have been directly transformed into treatment. The demand for treatment is not based just on the bare presence of signs and symptoms indicative of TMD; the frequency, intensity, duration, and disability has a significant influence also (Macfarlane et al. 2003). These factors may not only increase the reliability but also the clinical relevance in studies of TMD. Prospective studies based on non-patient samples have shown a fluctuating pattern of TMD symptoms and that individuals with such mild, and inconsistent symptoms rarely develop more severe TMD (Könönen and Nyström 1993, Carlsson 1999, Magnusson et al. 2000). The most commonly reported symptoms indicative of TMD were feelings of tiredness in the jaws and TMJ sounds, in agreement with many previous studies (Helkimo et al. 1972, Carlsson 1984, Wänman 1987, Salonen et al. 1990, Nydell et al. 1994, Wänman 1996, Magnusson et al. 2000). Notable was that almost twice as many (6.1%) reported frequent, intense, and longstanding dysfunctional symptoms as reported frequent, intense, and longstanding pain (3.8%). Since there seem to have been a gradual shift in the professions’ view on TMD from dysfunction to pain, these opinions may need to be reconsidered.

Impact on daily life

Remarkably small differences in the distribution of the rated intensities between the different symptoms were observed. Feelings of tiredness in the jaws were rated as almost as intense/disturbing as pain in the jaws. The symptom that was given the lowest intensity level was TMJ sounds. Seventeen percent stated that their symptoms indicative of TMD to some degree interfered with activities of daily living of which presence of frequent, intensive jaw pain of long duration had the highest impact, together with impaired jaw opening. The results are in accord with previous studies showing that patients with myofascial pain, arthralgia, or disc displacement without reduction have reported a higher impairment than patients with disc displacement with reduction (John et al. 2007, Reissmann et al. 2007, Rener-Sitar et al. 2008, Barros Vde et al. 2009). The results from the present study also resemble a previously reported, epidemiological study, where 14% of those with facial pain and 48% of those with severe headaches reported that, at times, they were unable to carry on some activities because of the pain (Von Korff et al. 1988). In a review on TMD and its relation to oral health-related quality of life, non-painful conditions had less impact on OHRQoL than painful conditions (Dahlström and Carlsson 2010). Among Sami women, TMJ sounds also dominated among those who stated no
disability related to the condition. The results indicate that most individuals, with non-painful joint sounds, adapt to the condition and thus are less disabled than they would be by painful conditions. Patients with myofascial pain more often used splints, consulted more physicians, and received more physiotherapy than patients with joint pathology (Schmitter et al. 2005). Sleep disturbances, impaired mood, and difficulties in chewing are other possible consequences of TMD pain (Murray et al. 1996). Even children with TMD symptoms report impaired quality of life, limited physical activities, and effects on their schoolwork and on activities with friends (Jedel et al. 2007). A higher absence from school and higher consumption of over-the-counter analgesics among adolescents with TMD pain were noted in a Swedish sample (Nilsson et al. 2009), as well as consequences for all aspects of their lives, even when the pain was absent the adolescents were constantly thinking of their pain (Nilsson et al. 2011). The incidence of pain in the jaw, TMJ and temple region seems to coincide with the early teen-age period (Nilsson et al. 2007). With reference to the negative consequences for the quality of life (Dahlström and Carlsson 2010, John et al. 2007, Anderson et al. 2011) affected individuals should be identified in the dental health care systems as early as possible.

Influence of age

The lowest prevalence of the pain conditions examined was observed in the oldest age group. This is in agreement with previous studies in which older individuals reported TMD symptoms less often than younger ones (Schmidt-Kaunisaho et al. 1994, Österberg et al. 1992). For headaches as well, young and middle-aged groups reported the highest prevalence and thereafter prevalence declined with age (Anastassaki et al. 2012, Radtke and Neuhauser 2009, Yekkalam and Wänman 2014a). Frequent as well as grievous TMD symptoms and headaches declined with age, but not the related disability stated on the NRS. The prevalence pattern of these symptoms in relation to age was quite similar, which may indicate a shared etiology. The prevalence of headache and facial pain among women peaked in 25- to 44-year-olds and was observed to be at lowest among the 65-year olds and older ages (Von Korff et al. 1988). A trend of continuing decrease in prevalence of TMD related symptoms in elderly has also been observed (Carlsson et al. 2014); 80-year-olds reported lower prevalence of such symptoms than 70-year-olds. These observations of declining prevalence of pain conditions from approximately the age of 60 and onwards are interesting in relation to the understanding of the phenomenon pain. Changes in levels of sex hormones after menopause (Fillingim 2000, Cairns and Gazerani 2009), changed stress levels and related behavior have been offered as explanations (List et al. 2001) but there may be other reasons. Future studies specifically addressing elderly and their beliefs about why pain conditions may decrease with age might help to generate new hypotheses on the subject. It is not inconceivable that differences in lifestyle between elderly and younger
generations of Sami women may account for some of the differences in pain prevalence. During the 1930s to 1950s, physical activity was a more normal part of the Sami daily life, than it is today (Nilsson LM. et al. 2011). Also a sedentary life in front of a computer constitutes a part of a normal weekday among many of the younger generation, which may constitute a risk factor for increased symptoms in the neck and, shoulders and for TMD (Perri et al. 2008).

The causes of age-differences are complex and probably related to both external and internal factors. Previous studies have shown that older TMD patients reported a greater negative impact on quality of life (John et al. 2007, Rener-Sitar et al. 2008) which supports the finding that despite age being significantly and inversely related to prevalence of TMD symptoms the estimated impact on daily life was not.

Co-morbid conditions

In this study on Sami women, significant relationships were found between symptoms in trigeminally and spinally innervated regions. Those included in the interview also considered the symptoms in the jaw-, head-, and neck/shoulder region as more or less unified. These observations confirms the results from previous studies (Wänman and Agerberg 1987, Schokker et al. 1990, Hasvold and Johnsen 1993, Ciancaglini and Radaelli 2001, Magnusson et al. 2000, Visscher et al. 2001b, Rantala et al. 2003, Wiesinger et al. 2007, Marklund et al. 2014) and indicates that these conditions are influenced by the same contributing factors and/or mutually affected or potentiated by each other. Co-morbidity between headaches and TMD pain has been observed already from the teen-age period of life (Nilsson et al. 2013). The lowest common denominator of these associations may be tooth-clenching habits, which beside the Sami women’s narratives also have been identified as a risk factor associated with frequent headaches in a prospective study (Marklund et al. 2014).

Headaches and NSP are common symptoms in the population (Bovim et al. 1994, Göbel et al. 1994, Unruh 1996, Côte et al. 1998, Scher et al. 1998, Rantala et al. 2003) and in accordance to the observations of the Sami women. Women report pain more frequently in these areas (Andersson et al. 1993, Bovim et al. 1994, Unruh 1996, Scher et al. 1998, Rantala et al. 2003), and they also report a higher degree of related disability than men do (Bovim et al. 1994, Unruh 1996, Webb et al. 2003, Unruh 2008). The prevalence of frequent headaches among the examined Sami women was close to figures previously presented in women (Agerberg and Bergenholtz 1989, Rasmussen et al. 1991, Boardman et al. 2003, Rantala et al. 2003, Yekkalamb and Wänman 2014a). The approximately 40% reduction in prevalence of headache that occurred when moderate to severe intensity level was added
as criteria resemble results presented in a previous study (Boardman et al. 2003). The prevalence of frequent (weekly) neck pain was lower in the Sami women than among 30–55 year old Finnish women (Rantala et al. 2003), but higher than reported for a general population sample in England (Webb et al. 2003), and close to the prevalence reported in a Norwegian survey (Hasvold and Johnsen 1993). In a Canadian sample, the 95% confidence interval for lifetime prevalence of neck pain, among both men and women, was found to be within 64%–70% (Côté et al. 1998). This was only slightly higher than among the Sami women in this study. Differences in how questions are constructed probably account for some of the variations in prevalence between the studies. Using the same questions, the one-year period prevalence of troublesome neck pain among women reached 40% in a Norwegian (Bovim et al. 1994) as well as in an Italian sample (Ciancaglini and Radaelli 2001). In the former study the prevalence was halved when only longstanding and troublesome neck pain was included. A pattern similar to that of the present study. When the criterion frequent (weekly), intense (moderate or worse) neck pain of at least five year’s duration and with a significant effect on daily life was added in an analysis the 95% confidence interval for prevalence of neck pain among women was 2.2%–5.4% (Webb et al. 2003), a figure significantly lower than in this sample.

Even in adolescents neck and back pain, have been significantly related to TMD pain (Nilsson et al. 2013). The severity of pain in the spinal region has been shown to affect the prevalence of TMD symptoms (both pain and dysfunction) in a mutual dose–response like pattern (Wiesinger et al. 2009). Reciprocity has also been found between the incidence of spinal pain and TMD signs in a prospective study on university students (Marklund et al. 2010b). Furthermore, it has been reported that patients with chronic craniomandibular pain often suffer from NSP and spinal pain (Visscher et al. 2001b). The exact causality of the observed co-morbidity is not known. The functional pattern shown between neck and jaw regions during rhythmical jaw movements indicates a synchronized motor control between the jaw and the upper spine (Eriksson et al. 1998, Eriksson et al. 2000), with activation of both jaw and neck muscles (Häggman-Henrikson et al. 2013). Stimulation of nociceptors in the temporomandibular joint area in cat activated the fusimotor-muscle spindle system of the dorsal neck muscles, suggesting that reflexes might be involved in the pathophysiological mechanisms responsible for the sensory–motor disturbances in the neck region often found in patients with temporomandibular disorders (Hellström et al. 2002). In healthy subjects the temporal coordination between the neck and the jaw system is high during normal jaw opening–closing movements (Eriksson et al. 2000, Zafar et al. 2000), but hampered in patients with a whiplash associated disorder (Häggman-Henrikson et al. 2002).
Chronic pain in the head and neck–shoulder region has also been associated with mood disturbances and perceived impaired general state of health (Linton 2000, Croft et al. 2001, Rantala et al. 2003, Bingefors and Isacson 2004, Carroll et al. 2004).

The present study showed that the estimates on the ADL scale for TMD symptoms was influenced by the intensity of neck pain, the estimate on the ADL scale for headache was affected by the frequency and intensity of feelings of tiredness in the jaws and the estimate on the ADL scale for neck–shoulder pain was influenced by the reported intensity of tiredness in the jaws. The individual’s cognition of the symptoms’ interference with daily life (which may indicate a higher state of severity) seemed to share a pattern of mutual impact similar to that between trigeminal and spinal symptoms. The results support previous observations on a relationship between neck disability and jaw disability in a sample based on subjects who attended a TMD/orofacial pain clinic compared to healthy subjects (Olivo et al. 2010). This study in Sami women thus gives support to the observations that symptoms in trigeminal and spinal regions are closely interrelated.

Case–control study

The reasons why women outnumber men as TMD patients are still not fully understood. Women may pay more attention to their health, and may have more sensitive perceptions of the symptoms, feel higher levels of disability and impact on social life, and experience the symptoms for a longer duration and at higher intensity than men do. Factors related to sex or gender may predispose or increase the vulnerability of women to developing longstanding pain and dysfunction, in general, as well as in the jaw–face region, which has powerful proprio- and nociception. Polymorphism of catecholamine-O-methyl transferase (Diatchenko et al. 2005) and serotonin (Ojima et al. 2007) as well as differences in the haplotypes of β receptors (Diatchenko et al. 2006) have been reported to be related to the development of TMD pain. This, together with the role of sex steroids and psychosocial factors, have formed the hypothesis of biopsychosocial mechanisms and increased vulnerability of certain individuals to developing pain and dysfunction in the jaw–face region (Diatchenko et al. 2006).

The significantly higher BMI of the cases may indicate that obesity is related to TMD in women. High levels of estrogen have been related both to higher BMI values (Olson et al. 2006) and to TMD pain (LeResche et al. 1997b). The link may thus relate to female hormones, physical activity levels, or both, and warrants more research.

Factors that induce increased physical loading on the tissues involved may be individually significant and related to the individual’s reaction patterns and capacities (Wänman and Agerberg 1991). One major difference between cases and controls with regard to clinically registered variables was the pain
elicited when loading the muscles and the TMJ. One of the first studies to find differences between cases and controls with regard to submaximal clenching was that of Clark et al in 1984 (Clark et al. 1984). The finding of pain reactions on TMJ loading may indicate that the prevalence of arthralgia was higher than indicated by the RDC/TMD classification schema, in which tenderness to palpation over the joint area is an obligate criterion. The cases also presented a significantly higher proportion of pain reactions to palpation. These signs are often interpreted as indicating myofascial involvement, although recent research indicates that they may be inferred as indicating a reduced pain threshold to pressure (Svensson and Arendt-Nielsen 2000).

No major differences in the state of dental occlusion or variations in the specific examined occlusal factors were observed between cases and controls. The result thus support the opinion that factors in the dental occlusion do not have a predominate role in the perpetuation of musculoskeletal symptoms in the jaw–face region. The results are in line with the results of most previous epidemiological studies, which demonstrate that a similar variability of dental occlusal factors exists among subjects with and without TMD (Carlsson GE 2010). Contradictory results have also been presented. Artificial interferences were attached to the teeth in TMD patients previously treated with positive outcomes, and in controls. The study showed that the patients were more vulnerable to develop symptoms and more sensitive to the change than the controls (Le Bell et al. 2006). Some factors in the dental occlusion were identified as risk factors for incidence and persistence of TMD in a prospective study (Marklund and Wänman 2010a). The authors of the latter study expressed that a too simplistic view of the dental occlusion may be harmful to the individual patient with longstanding TMD signs and symptoms. Studies investigating causation should have a prospective design. Further, well controlled, and prospective studies in the future may help us to decide if the “occlusal door” should be ajar or closed.

Persistent pain in the jaw–face region may be caused by a focal neuropathic pain disorder (Clark 2006). Idiopathic pain conditions in the face are bothersome for the patient and difficult to manage. It has been hypothesized that neuropathic pain disorders may be related to changed perception of tactile stimulation (Jacobs et al. 2002). The tactile thresholds in the trigeminal innervated regions were thus tested with von Frey monofilaments. The cases and controls, however, responded uniformly to the tactile perception test. From my clinic experiences, patients with severe idiopathic facial pain conditions can present signs of both hypo- and dysesthesia in the painful region of the face. One interpretation of the result may be that the population of approximately 500 included women was too small to capture such cases. The prevalence of these conditions may thus be counted per thousand.

Women with TMD considered their general health status as more impaired than that of the controls which supplements and confirms the results of
previous studies (Agerberg and Carlsson 1975, Johansson et al. 2004, Yekkalam and Wänman 2014b). The significant and high likelihood of reporting impaired health among the cases was interesting, since the proportion of those under medical care due to disease did not differ significantly between cases and controls. This result should not be interpreted a direct correlation between the experience of symptoms in the jaw–face region and impaired general health. There may be several confounders of the results, such as co-morbid pain in other locations, with related sleep disturbances (Lobbezoo et al. 2004) and psychological distress (Visscher et al. 2001a).

**Thematic interviews**

*Experiences of TMD*

In the interview a choice was made to display a variety of beliefs towards and experiences of jaw, neck, and shoulder pains from the Sami women’s non-expert perspective. All informants with TMD also had neck and shoulder pains, headaches and tinnitus, and described, expressed, and regarded all these symptoms as a more or less unified condition. The pathophysiological background of such perception may be attributed to convergence of trigeminal and cervical nerves in the brainstem (Sessle et al. 1986, Piovesan et al. 2003). The women without TMD, headaches and NSP contributed with their thoughts regarding triggering factors, strains, distrust, and reconciliation. Most triggering factors were described in terms of inflicted injuries, but behavior, heredity, and life circumstances were all proposed and fit with the biopsychosocial model (Suvinen et al. 2005, Gatchel et al. 2007). The model could therefore be used as a model for shared understanding in patient information and treatment sessions.

*Proposed causes of TMD*

A common statement among the participants with TMD symptoms was that they were aware of clenching their teeth together. Bruxism (tooth clenching and/or grinding) is one proposed etiological factor of TMD. The participants comprehended that their biting behavior was a cause of their TMD problems. Several studies have found relationships between reported bruxism and TMD (Glaros and Burton 2004, Svensson et al. 2008). This relationship has, however, been questioned with reference to the weakness in self-reported bruxism and analyses mostly based on cross-sectional samples (Molina et al. 2000, van der Meulen et al. 2006). In a fairly recent systematic review on bruxism and temporomandibular disorders (Manfredini and Lobbezoo 2010b), the authors concluded that self-reported bruxism was associated with TMD pain, but that studies using more specific methods to diagnose bruxism showed weaker association with TMD symptoms. The present study
DISCUSSION

... gives support to the existence of a relationship between TMD and tooth clenching habits, based on the participants’ narratives and experiences. A habit of long-term, low-level clenching (holding teeth tightly together) might thus be a significant factor in the development of longstanding TMD (Glaros et al. 1998, Glaros and Williams 2012). In the case-control study, the cases significantly more often reported awareness of tooth clenching habits than the controls. Even a light clenching effort, referred to a tooth contact habit with the maxillary and the mandibular teeth continuously in contact with minimal force in a nonfunctional situation (Sato et al. 2006), may cause strain of the TMJ and masticatory muscles. A habit of maintaining tooth contact has been noted as a risk factor for development of myofascial pain (Michelotti et al. 1997, Chen et al. 2007). The strain may cause injury of muscle fibers and reduce the blood supply to the muscle since perfusion is impaired during clenching (Kim et al. 1999, Buzinelli and Berzin 2001, Svensson et al. 2001, Nakamura et al. 2005). One of the most commonly reported symptom in the questionnaire study, was feelings of tiredness in the jaws which may be an effect of habitual nonfunctional tooth contact activity. The results are thus in line with previously found associations between oral parafunctions and TMD (Magnusson et al. 2000, Jacobs et al. 2002, Johansson et al. 2004, Marklund and Wänman 2010), indicating that these jaw motor behavior patterns, especially tooth clenching and tongue pressing, are significant in patients with TMD.

Distrust in healthcare

The Sami women shared experiences of distrust of both medical and dental health care services. Similar results were found in a qualitative study of chronic orofacial pain patients referred to a pain clinic (Wolf et al. 2006). The orofacial pain patients, however, expressed anger and frustration and regarded their pain as elusive. Such strong expressions were not used among these Sami women. This difference may be related to differences in the explicit dental health care situations and related expectations. Participants in the orofacial patient sample also expressed feelings of helplessness and a need to be taken care of (Wolf et al. 2006). The Sami women, on the other hand, indicated empowerment in their self-management and coping strategies, and gave examples of factors that provided them at least temporary pain relief. Both of these studies, however, indicate that the consultations are a critical event, which at least among those with longstanding pain has not favored recovery and rehabilitation. In an article by Eccleston and co-workers, responsibility, blame, and identity protection among pain patients and professionals were unfolded (Eccleston et al. 1997). The consequence of not being believed, and questioned, severely damages the trust between patient and caregiver. Such experiences may even prolong the pain and are less likely to motivate the patient to adherence to suggested
treatment strategies. The consultation event thus seems to be a potential area for development among physicians and dentists. The caregiver should pay attention to the patient’s own thoughts and beliefs, since this could be a good point of departure in the rehabilitation process.

**Health aspects**

Most participants shared thoughts regarding the healing and reconciliation processes. For these women, good health was equal to, and a prerequisite for, independence and freedom. The ability to work was thus an important keystone, together with the vision of physical fitness. Access to nature was also important. The participants reported various types of physical activities such as walking, running, skiing, and taking part in group training. Exercise is also recommended as an important part of rehabilitation in patients with chronic pain (SBU 2006). A study from the north of Norway showed that ethnic origin had an impact on the level of physical activity. Sami women were more active than the Norse women (Hermansen et al. 2002). The results indicated a common understanding of exercise being an important part of a coping strategy to stay healthy. All people are probably, at some point of their life, subjected to various strains, related to physical, psychological and/or social difficulties. The ways people succeed in facing these difficulties varies. Despite similar level of strains, some manage to stay healthy while others do not. Some of the results from the interviews can be viewed from a salutogenic perspective as proposed by Antonovski, (Antonovsky 2005). His model focuses on people’s resources and abilities to resist adversities, maintain health, and cope with negative stressors. An individual's capacity to handle stress and diseases depends on the extent to which life is experienced as meaningful, manageable and understandable all important keystones in the concept of sense of coherence. The Sami women, described difficulties, strains and life stressors, but some obviously remained healthy. The women without TMD described a social context in which they felt secure and presented various strategies to cope with strains. They described a strong social support, in accordance to the salutogenic model. It has been reported that a strong sense of coherence is associated with better health-related quality of life and self-efficacy as well as less catastrophizing thinking in patients with chronic pain (Chumbler et al. 2013). It was further concluded that sense of coherence may be an important factor for patients with chronic musculoskeletal pain. Efforts to strengthen empowerment and self-efficacy in individuals with pain and dysfunction in jaw, head, and neck, may be fruitful for both the individual and the society. I thus consider further studies with salutogenetic perspectives important, to gain increased knowledge in factors of importance for maintenance of the good health.
Clinical implications and future perspectives

My vision of this research project was to follow a path of discovery from the answers in a questionnaire down to the individual perspective among Sami women. The gender perspective was chosen, since women outnumber men as patients with TMD, and the Samis, since available surveys were limited when the project started, and because they may be regarded as a fairly homogenous population. The latter assumption may, however, be questioned.

In general terms, the observed prevalence of conditions examined was briefly in line with other population-based studies conducted during a fairly similar period, indicating that the findings are not specific to the Sami women, but may be considered valid for women in general. The results support previous studies on TMD and its dependence on age, affect on quality of life, relationship to other pain conditions, and awareness of oral parafunctions among the affected.

From the narratives it was evident that many of the women with longstanding pain in the jaw–face region had been treated with bite splints, but they were not quite convinced about the effect. Splints are today advocated as a treatment of choice, and their positive effect has been shown in several studies (Swedish guidelines for dental health care in adults). There is, of course, no universal treatment effective for all individuals, and perhaps the selected women were those who did not respond to previous treatment strategies. Splints may be viewed as a fairly passive and conservative treatment approach. If the patient is not fully motivated, her compliance with the treatment may be hampered. From these perspectives an approach by dental health care providers that includes active listening, confirmation, motivation, and individually adjusted information is essential to build trust and reconciliation and improve adherence to treatment regimes.

The management should be supportive and enhance the patient’s empowerment and self-efficacy to handle stress and strain and to take active part and responsibility in the rehabilitation process. An understanding of the patient’s social context and support should also be taken into consideration. A multidisciplinary approach is advocated for more severe cases, since the women with longstanding and more severe TMD also were affected by headaches, neck–shoulder pain, and tinnitus. The remuneration system for treatments of these patients in dental and medical care should, accordingly, for this group of patients be the same. Future studies should try to find answers to explain factors related to the observed decline of TMD symptoms and headaches with age. Rehabilitation in groups may be tested in patients with disabling TMD to elucidate whether that context can improve a sense of coherence, self-efficacy, and coping strategies for the benefit of the patient.
Summary of results

This investigation among Sami women in Arctic Sweden showed that

- Symptoms indicative of temporomandibular disorders, headaches and neck–shoulder pain were frequently reported and showed comorbidity in a cross-sectional analysis.

- The most commonly reported symptoms indicative of temporomandibular disorders were feelings of tiredness of the jaws and temporomandibular joint sounds.

- The prevalence of symptoms indicative of temporomandibular disorders and headaches diminished with age.

- Symptoms indicative of temporomandibular disorders, headaches, and neck–shoulder pain influenced daily life negatively. Seventeen percent of the Sami women reported some disability related to their symptoms indicative of temporomandibular disorders.

- Factors related to pain had the greatest influence when these Sami women rated the related impairment.

- The individuals’ cognition of the symptoms’ interference with daily life showed a pattern of mutual influence between trigeminal and spinal areas.

- Longstanding, severe, and frequent symptoms indicative of temporomandibular disorders remained essentially unchanged over a two-year follow-up period.

- In the examined cases, a diagnosis according to the Research Diagnostic Criteria for Temporomandibular Disorders classification was established in 59%, and 91% had signs of dysfunction according to the clinical dysfunction index.

- An impaired general state of health was commonly reported among women with temporomandibular disorders

- The state of the dental occlusion was similar between the TMD cases and controls.

- Women with TMD symptoms expressed awareness of habits of biting/holding teeth together, and a limited social support.
Conclusions and generated hypotheses

- Women are commonly affected by symptoms in the jaw, head, and neck–shoulder region. Both pain and dysfunction symptoms in the temporomandibular region are related to disability and interference with daily life.

- Sami women with longstanding TMD symptoms related their symptoms to fairly simple triggers and a more or less consistent jaw-clenching behavior, indicating that relieving such behaviors and related strains should be an essential element in treatment of patients with TMD.

- Co-morbidity between symptoms in trigeminally and spinally innervated regions may affect both perpetuation of symptoms and related disability. This indicates that in management of patients with such symptoms, pain and dysfunction in both regions should be taken into consideration.

- Women with TMD, associated headaches, and NSP may benefit from empowerment of their self-efficacy to handle stress and strain and also to take active part in their rehabilitation. An understanding of the patient’s social context and support may, in that coherence, be crucial to the outcome.

- An approach by health care providers that includes active listening, confirmation, motivation, and individually adjusted information may help to build trust, reconciliation and improve adherence to treatment regimes. Group rehabilitation may also be tried in patients with disabling TMD to elucidate whether that context can improve a sense of coherence, self-efficacy, and coping strategies for the benefit of the individual patient.
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References


REFERENCES


Sjölander, P. (2011) What is known about the health and living conditions of the indigenous people of northern Scandinavia, the Sami? *Glob Health Action, 4*.


REFERENCES


