DIPLOMA THESIS

Title of the Diploma Thesis

“The Stigma of the Eagle-Syndrome and its Impact on Social Relation Ships”

submitted by
Nora Sophie Aigner

in partial fulfilment of the requirements for the degree of
Magistra der Philosophie (Mag. phil.)

Vienna, 2019

Degree programme code as it appears on the student record sheet:	A 190 347 299
Degree programme as it appears on the student record sheet:	Teacher studies in the subjects French & Psychology/Philosophy
Supervisor:	Mag. Dr. Andreas Olbrich-Baumann

Acknowledgement

At this point I would like to express my sincere gratitude to all those who have contributed to the completion of my studies, my medical care, as well as to the writing of this thesis.

Special thanks go to my supervisor, Dr. Andreas Olbrich-Baumann, who placed trust in me from the very beginning, awakened my interest in scientific research and supported me in my project with a high level of expertise and accuracy.

I would also like to thank my physiotherapist Prof. Dr. Harry von Piekartz from the Netherlands, who supported me both professionally and emotionally in a phase of upheaval. Without his commitment, this work would not have been possible in the first place.

I would also like to thank all my doctors who have provided me with continuous medical care since I interrupted my studies or continued my studies. I would like to mention them all by name, but 45 names are unfortunately too many for the preface☺.

I would like to thank my therapists for doing their best every day and continuing to do so in order to reduce my pain (especially Sylvia F., Anita Z. MSc. , Anita Z. MSc., Martha N. , Manuela K., Silvia K. MAS, Maria L., Katharina L., Andrea G., Shallu B. and Robby H. , Mag. Franz H., Wolfgang M. Manfred Z.)

To my cousin Kirstin, I want to say thank you for her encouragement, and for energetically taking care of my physical and mental condition since the final phase of my studies. I would love to have half of her strength!

I would like to thank my colleague Bernhard for his perseverance and patience in helping me with the statistical evaluations, which was only possible through purely *non-verbal* communication due to my limited speaking capacity.

I would also like to thank my friends, acquaintances and relatives for the emotional and financial support of my family (especially Aunt Petra, Aunt Lisbeth and the Iciren family).

Furthermore, I would like to thank my loving grandparents Helene & Otto and Herma & Willi, whom I have looked up to since childhood. Their continued belief in me was sometimes a great motivation to complete my studies.

A special thank you goes to my sister Lisa, who has been a role model and good example for me throughout my studies and has not been afraid to set a high bar for me at all times.

She spurred me on along the way, guided me with warm-heartedness and confidently prepared me for hurdles of all kinds.

Last but not least, I would like to say a special thank you to my parents Doris & Albert, who *taught* me from an early age how important values like (family) cohesion and humanity are in life, besides knowledge acquisition and education. Their support has enabled me to fly 42 times in the last 2 years, to undertake 28 medical therapy trips to 15 cities and 8 international teaching institutions in America and Europe. With the goal of gradually regaining my health, I have also been able to gather ideas for this work. Even though this goal has not yet been fully achieved, I have already been able to gain experience from which I hope to learn as much as possible for my future.

Vienna, July 2019

This work is dedicated to all those people,

who are in some form of grief.

Abstract

This diploma thesis examines women with chronic pain in the throat-head region and therefore focuses on two different diseases: the temporomandibular disorder (TMD) and the rare Eagle syndrome. Studies of Lennon et al. (1989) demonstrated that TMD patients who seek treatments often perceive stigmatization as a result of their disease, which can negatively affect social relationships. This diploma thesis aims to investigate if this also holds true for patients suffering from the Eagle syndrome. The ultimate research question was: "Do Eagle syndrome patients feel as stigmatized as TMD patients because of their disease and does this have negative consequences on their social life?

For this purpose, a quantitative survey was conducted and accessible for both patient groups all over the world. Overall, 63 female participants of Africa, Asia, Australia, Europe and North America participated (42 ES, 21 TMD). The results demonstrate that there is no difference in the perception of stigma with regard to both diseases. Eagle syndrome patients also feel stigmatized and estranged due to their pain. They show a high number of variously consulted health professionals (14), are less satisfied with their social life and have a lower social interaction. Furthermore, both patient groups experience severe social and emotional loneliness.

Public campaigns could raise the level of awareness of the Eagle syndrome and improve the clinical approach as well as the development of further, possible cures. This might also be an important step in avoiding a number of negative consequences caused by this disease.

Table of contents

List of figures

List of tables

1 Introduction

This diploma thesis deals with people who suffer from chronic pain and therefore have to cope with their lives in an extraordinary way. For the socio-psychological study on stigmatisation and its influence on social relationships, two diseases in the face/neck/head area were chosen: the rare "Eagle syndrome" (=ES) and the more common temporomandibular dysfunction (=TMD). These two conditions were chosen because they both cause pain in a similar physical region, but have different symptoms and causes.

A 1989 study by American researcher Mary Clare Lennon of the City University of New York showed that TMD patients entering clinical treatment are vulnerable to stigmatisation and therefore often have strained social relationships (Lennon et al. 1989).

Based on this finding, the largely unknown Eagle syndrome will be examined with regard to its stigmatisation potential and the associated effects on the social life of those affected.

This study is the first research worldwide that deals with the socio-psychological aspects of Eagle syndrome. During data collection, care was taken to ensure that the study was as accessible as possible, so that patients from all continents could participate. Personal concern and the desire for clarification provided the impetus for dealing with the topic.

The thesis is divided into two halves. The theoretical part intends to inform about the current state of research of the two diseases. After the clinical classification at the beginning, the theoretical part is mainly dedicated to the patient group with a temporomandibular disorder, as there have only been a few medical case studies on Eagle's syndrome up to now. The literature is therefore mainly based on findings about TMD. The theoretical part is enriched with verbatim quotations from TMD patients in order to provide an authentic insight into the lives of the patients. The living conditions of the second group of Eagle syndrome patients will be analysed in the empirical part.

The work is structured as follows:

First, the topic of "chronic pain" and its significance for both study groups is discussed (chapter 2). This is followed by a discussion of stigmatisation and how this comes about in chronically ill people who search for suitable therapy methods for a long time (chapter 3). Subsequently, the consequences of chronic pain for the patients' social life are presented (chapter 4).

The theory section is followed by the empirical part. At the beginning, the methodology and operationalisation of the explanatory study are described in detail (chapter 5). The results form the core of the thesis and are documented and interpreted in detail (Chapter 6). In a discussion, the problem and hypothesis are finally clarified and the research question is answered (Chapter 7). Finally, a summary sums up the most important findings, whose relevance for science is highlighted in conclusion. After the bibliography (chapter 8), the appendix contains the questionnaires used (chapter 9).

Since the research groups are exclusively composed of women, the work will mostly refer to female persons. Thus, it is intended that counter-gendered formulations occur only rarely.

2 Chronic pain - two diseases in focus

According to the International Association for the Study of Pain (IASP), pain is a sensory and emotional experience that is perceived as unpleasant and is related to potential or actual tissue damage (Schmidt & Struppler 1982). If one starts from those pains that are experienced physically (in distinction to "mental" pain experiences such as homesickness, lovesickness, etc.), then pain as a physical experience has to be seen as a physical experience.), pain as a physical phenomenon nevertheless has significant emotional aspects. Pain is in fact much more than a purely sensual perception of stimuli (Kröner-Herwig 1996).

Pain can basically be categorised into several forms. In order to follow the elaboration of the present study, it is important to differentiate between two types:

On the one hand, there is **acute pain, which is** a vital function for humans, as it informs them about threatening processes in/on their body such as injuries, inflammations or wounds. On the other hand, there is **chronic pain, which** is determined by the fact that it persists over a longer period of time (according to Merskey 1984 at least 3 months).

The two forms of pain thus differ in the permanence of their symptoms. Acute pain signals usually disappear as quickly as they occurred, as soon as the irritation has subsided and the wound has healed. In chronic pain, on the other hand, the pain persists even though it no longer represents a warning function for the individual. They thus create their own clinical picture.

The present study focuses on two diseases that usually have a chronic course, especially since they cause pain that is difficult to treat. The focus will thus be on the significance of the chronic form of pain. Persistent pain can affect all areas of the life of those affected, as their everyday life is considerably influenced by the experience of pain. Moreover, persistent pain is an extremely negative experience for sufferers not only on a physical level, but also in a psychosocial context (Kosinski et al. 2005).

Based on numerous studies, we now know that chronic pain triggers considerable distress. This in turn can lead to anxiety, anger, depression, sleep disturbances, loneliness, significantly lower quality of life and altered self-image and identity (Hazaveh & Hovey 2018; Hoffman & Meier 2002; Carson et al. 2005). The following sections will now provide an insight into the state of research on the two diseases that are relevant to this paper.

2.1 The Eagle Syndrome

2.1.1 Definition and epidemiology

Eagle syndrome is an organic disease of the neck and belongs to the group of "rare diseases". Eagle's syndrome, also called stylohyoid syndrome, is an elongated bony *process (lat.: processus styloideus)* and/or a calcification/ossification of a *ligament (lat.: ligamentum stylohyoideum*) that leads from the base of the temporal bone to the hyoid bone (Austrian Medical Society for Neural Therapy and Regulation Research 2016). Normally, the length of the bony process is 2.5 - 3cm. Anything beyond this can lead to painful symptoms of Eagle's syndrome (Eagle 1937).

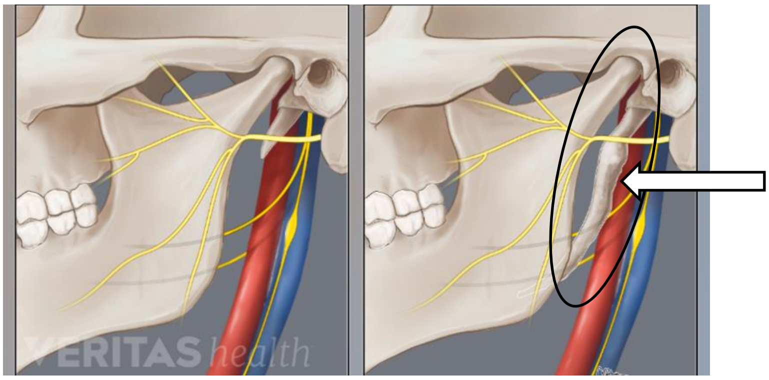


Figure 1: Normal styloid process (left) vs. lengthened styloid process (right) [1]

It is assumed that about 4% of the population have an elongated penile process, but only a small percentage (about 4% of the 4%) suffer from its symptoms. Thus, the rate of the syndrome is 0.16% (Ilguy et al. 2005).

It usually affects middle-aged people between 30 and 40 years of age, mainly women. The bone processes can be elongated on both sides, but this does not automatically mean that the pain cannot also occur on one side only (Strauss & Glaser 1985).

There are basically 2 types of the syndrome. In "Classic Eagle Syndrome", the calcified ligament/overlong bone causes compression of the nearby cranial nerves, which in turn causes pain and various symptoms. The so-called "styloid carotid syndrome" is also caused

---

[1] Source Figure 1: https://www.spine-health.com/conditions/neck-pain/neck-pain-eagle-syndrome (6.5.2018).

by the bone spur, which in this case exerts pressure on the surrounding carotid arteries. Due to the mechanical effect, these are squeezed and various non-specific symptoms appear (Soldati et al. 2013).

2.1.2 Cause and symptoms

According to the Austrian Medical Society for Neural Therapy and Regulation Research (2016), the symptoms of (Classic) Eagle Syndrome include:

- vague sore throat
- atypical facial pain
- Palpation pain (=pressure dolence in the area of the jaw angle)
- Globus sensation (=feeling of a foreign body in the throat, which is particularly obstructive when swallowing)

According to Taheri et al. (2014), in addition to sore throats and constant pharyngeal pain in the area of the tonsils, the following are also characteristic:

- Dysphagia *(lat.: swallowing disorder)*
- Dysphonia *(lat.: voice disorder)*
- Cough
- Changes in the voice
- Otalgia *(lat.: earache)*
- Neck pain, headache, dizziness

and according to Baugh and Stocks (1993):

- Pain on head rotation and neck movement &
- Pain on tongue movement/extension

According to the Austrian Medical Society for NT and RT (Österr. Med. Gesellsch. f. NT and RT (2016), the so-called hyoid tendinopathy, which is understood to be a malfunction of the hyoid muscles in the throat, occurs together with the symptoms described.

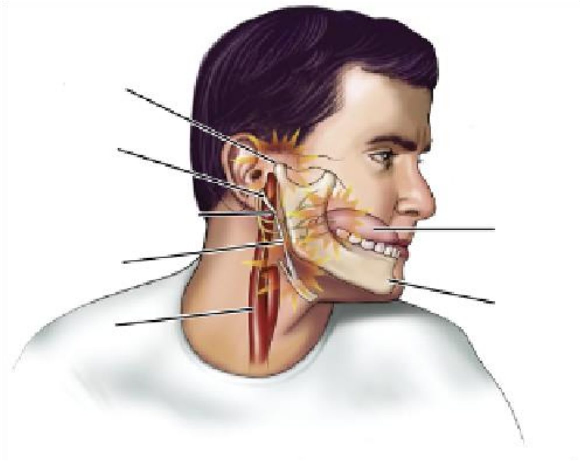


Figure 2: Pain localisation of Eagle's syndrome [2]

Due to the delicate anatomical structures surrounding the bone, the disease experiences a particularly complex clinical significance. The bony process lies close to the internal jugular vein and between the internal and external carotid arteries, which supply the skull, the upper neck organs (larynx, thyroid, pharynx) and the hard meninges. Three different muscles lead away from the process, each of which is innervated by three different nerves. In addition, there are 5 important cranial nerves around the styloid process, which are (von Piekartz 2015):

- Facial nerve (lat.: facial nerve, 7th cranial nerve)
- Glossopharyngeal nerve (lat.: tongue-pharyngeal nerve, 9th cranial nerve)
- Hypoglossal nerve (lat.: hypoglossal nerve, 12th cranial nerve)
- Spinal accessorius nerve (lat.: accessorius=accessor, supplies the trapezius and cephalic nerve, 11th cranial nerve)
- Vagus nerve (lat.: vagari=to wander around, largest nerve of the parasympathetic nervous system, supplies the pharyngeal muscles, laryngeal muscles, mucous membranes of the glottis, taste receptors, the atrium of the heart, lungs, stomach, liver, kidneys, etc., 10th cranial nerve).

---

[2] Source Figure 2: http://pocayo.com/Tutorial/topic-194/Atlas-of-Uncommon-Pain-Syndromes-35.html (5.5.2019).

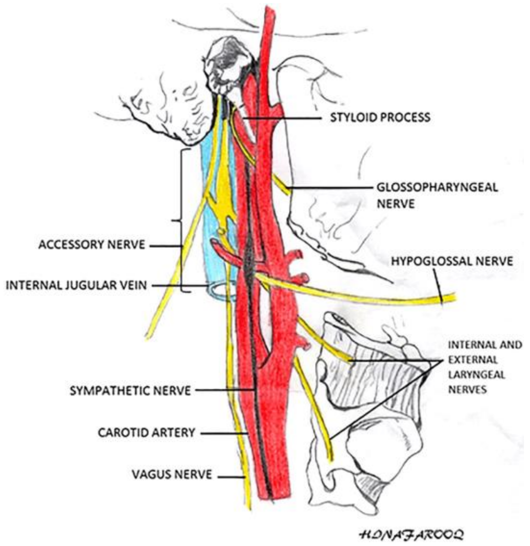


Figure 3: Anatomical structure around the stylet process [3]

As already mentioned, the excess length of the bone leads to mechanical pressure on the neighbouring structures. This leads to stimulation of the nerves, which triggers irritation and pain signals and, in the next step, provokes inflammation (Taheri 2014). Since several nerves, muscle groups and blood vessels can be affected at the same time, there are a large number of different symptoms, which makes diagnosis difficult.

Little is known in the literature about the actual cause of the disease, especially as the process of bone formation is still unclear. Possible factors such as congenital elongation, ossification of the tendon-like ligament due to unknown processes or the growth of a bone tissue at the attachment of the tendon are suspected (Murtagh et al. 2001).

Other theories discuss bone fractures due to trauma, which in turn can exert pressure on the surrounding structures (nerves, muscles, blood vessels), inflammatory changes or irritation of the pharyngeal mucosa - also due to tonsil operations and the resulting scars. However, the exact cause remains more or less unknown (Murtagh et al. 2001).

---

[3] Source Figure 3: https://www.researchgate.net/figure/ICA-and-its-relation-to-cranial-nerves-IXth-Xth-XIIth-and-sympathetic-chain-bracket_fig5_308882035 (6.5.2019).

2.1.3 Diagnostics and therapeutic approaches

In the best case, palpation (palpation of the neuralgic area) should be able to raise the suspicion of an elongated styloid process in the course of a physical examination after a suitable pain description and anamnesis of the patient. Imaging techniques such as a panoramic X-ray are often used to confirm the suspicion (Murtagh et al. 2001). The most reliable diagnostic method has proven to be the three-dimensional CT scan of the cervical-cranial region, which can provide exact information about the actual length of the bony processes and their angulation (Bouzaïdi et al. 2013).

Figure 4: Elongated styloid process/calcified stylohyoid ligament, lateral view [4]

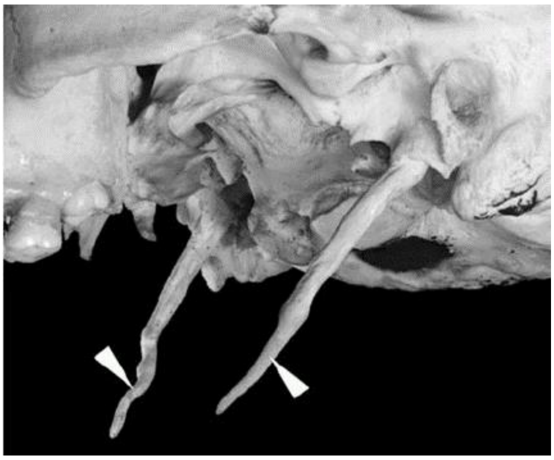


Figure 5: Bony processes on both sides

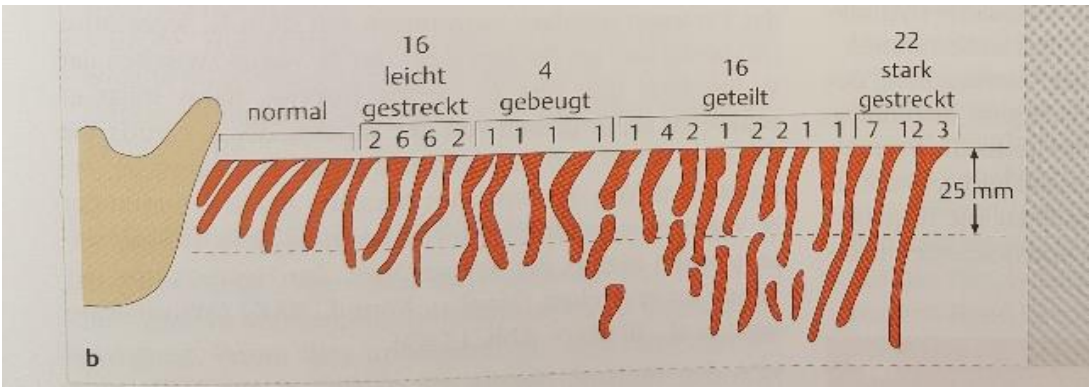


Figure 6: Angulation of the extension [5]

---

[4] Source Figure 4 & 5: http://www.hasznaltmobil.info/mmp/s/stylohyoid-ligament-ossification/ (5.5.2019).

[5] Source Figure 6: Von Piekartz,Harry J. M. Jaw, facial and cervical region. 2015.

According to Von Piekartz (2015), conservative approaches are preferred to surgery as a treatment measure, especially as this is associated with a certain risk. For example, infiltrations of steroids or local anaesthetics are said to serve to locally anaesthetise the pain region. Sedatives or antidepressant drugs are also considered a possible approach to dull the pain stimuli. However, the conventional, non-surgical methods have proven to be inefficient (Ceylan 2008).

If conservative pain therapy is not effective, resection (=removal) of the overlong bone or surgical shortening of the ossified ligament in the course of an operation is indicated (Österr. Med. Gesellsch. f. NT und RT 2016).

However, due to the delicate anatomy of the cervical-skull area, it is not without danger. Thus, there are two ways to perform the procedure. On the one hand, the bones can be removed extraorally through incisions on the outer neck area, on the other hand, there is the way of an intraoral operation via the oral cavity. The intraoral technique is considered more precarious in the literature, especially since it carries a higher risk of infection and must be performed under a low field of vision (Strauss 1979).

Figure 7: Intraoral surgery [6]

Figure 8: Extraoral surgery [7]

---

[6] _Source Figure 7: http://www.omjournal.org/IssueText.aspx?issId=84 (6.5.2018).

[7] _Source Figure 8: https://www.peertechz.com/Otolaryngology-Rhinology/AOR-3-135.php (6.5.2018).

The wide range of different symptoms, the low prevalence in the population and the associated low level of awareness of the syndrome usually delay the diagnosis. Doctors often confuse the symptoms with toothache or TMJ disorder (Blackett et al. 2012). According to several studies, Eagle syndrome is therefore often overlooked or misdiagnosed (Prasad et al. 2002).

Many patients have suffered for years until they are correctly diagnosed and have a high frequency of visits to the doctor as they seek explanations and solutions for their complaints.

2.2 Temporomandibular dysfunction

2.2.1 Definition and epidemiology

Temporomandibular dysfunction (TMD), also known as TMJ (temporomandibular joint dysfunction), is a collective term for dysfunctions in the area of the *temporomandibular* joint *(Latin: mandibula)*, starting from the temporal bone *(Latin: temporo)*. Temporomandibular dysfunction belongs to the group of musculoskeletal disorders and causes pain in the orofacial region that cannot be explained by toothache (Bell 1989). TMD is a functional disorder that affects either the muscles of the masticatory apparatus, the temporomandibular joint itself, or both (McNeill 1993). Numerous subcategories complicate the definition and thus the diagnosis. In the literature, one finds many criteria according to which the individual forms can be classified. However, it can be irritating that this type of facial pain is often associated with the abbreviation CMD. This is derived from the English term "craniomandibular dysfunction", is partly associated with similar symptoms, but at the same time includes pain in the area of the entire skull *(Latin: cranium)*. For the present work, only the term temporomandibular dysfunction (TMD) is used, as this is more specific and does not extend the pain localisation to the whole head like CMD.

The condition is more common in women (Drangsholt & LeResche 2009) and most often affects people between the ages of 20 and 40 (Wright & North 2009). About 33% of the population have at least one TMD symptom during their lifetime. Approximately 3.7% - 7% of the population suffer from such severe symptoms that they seek medical treatment (Wright & North 2009). In this study, the target population is the latter group. These are those patients who are looking for appropriate therapeutic measures due to intense existing pain.

2.2.2 Cause and symptoms

The literature describes several forms of symptomatic signs and possible explanations for their occurrence.

The most common form is disc dislocation with reduction. This is a misalignment of the temporomandibular joint that can often result in sounds such as the joint cracking or a limited range of motion when it is used. However, few people with this diagnosis find this misalignment so bothersome or restrictive that they would seek treatment (Wright 2010).

The situation is different with so-called "myofascial pain", which is a form of muscle pain in the area of the jaw. This is the most common diagnosis (Sato et al. 1997). Patients suffering from this type of pain are the most likely to seek appropriate treatment. The pain is described as a feeling of pressure or as dull, but can also be experienced as pulsating and throbbing (Fricton 2007). It occurs mainly in the sphincters of the mouth, which are:

Masseter *(Latin: masseter muscle)*, temporalis *(Latin: temporal muscle)* and pterygoideus medialis *(Latin: inner wing muscle)*. These are sensitive to palpation, especially as sensitive trigger points are usually located there (Sciotti et al. 2001).

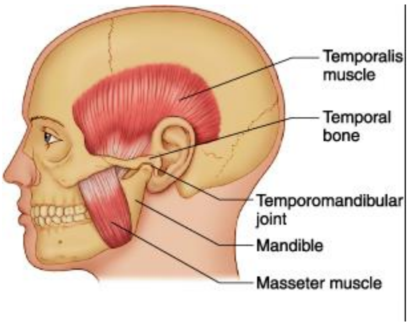


Figure 9: Pain localisation of TMD [8]

In addition to this type of muscle disease, there are other forms such as myositis, which is an inflammation of the muscles of mastication due to infection or trauma, or myospasm, in which there are severe spasms in the jaw region due to muscle contraction, and several other subcategories and myalgias, in which there are sometimes only minor distinguishing features (Wright 2010).

---

[8] Source Figure 9: http://maxremedial.com/blog/2015/10/16/tmj-the-sneaky-symptom (6.5.2019).

Another category that should be mentioned here, as it is often associated with chronic pain in the facial region, but strictly speaking should be distinguished from temporomandibular disorder, is atypical facial pain and trigeminal neuralgia caused by nociceptive stimuli. It is believed that compression of the 5th cranial nerve called the trigeminal *nerve (Latin: triplet nerve)* can cause mostly unilateral, sharp stabbing, intense burning, neuropathic pain in one or all 3 branches of the nerve (Zakrzewska 2002).

In a study, it was also found that patients suffering from temporomandibular dysfunction also have an increased lengthening of the styloid process (de Andrade et al. 2012).

As can be seen from the above list, the pain localisation of all described symptoms primarily affects the face, the jaw, the area around the ears, but can radiate to the tongue, the neck, the upper head area as well as to the shoulders.

Mechanical pain triggers are therefore any movements that take place in this area: Chewing, eating (especially hard meals), talking, yawning, grinding the teeth (=bruxism), and much more. ,...

However, since the original origin of this disease is unknown, it is assumed that the pain may have psychogenic triggers in addition to biological causes. The psychosocial condition of TMD patients therefore plays a role that should not be underestimated.

Wittink (2002) describes in his study on chronic pain that pain experiences can be triggered by emotional mechanisms as well. Numerous studies have therefore been conducted to investigate the relationship between psychopathological factors and pain in the orofacial region.

It is easy to understand that stress is closely related to temporomandibular disorders. Prolonged stressful situations or anxiety can lead to alarm reactions in the body, which are accompanied by increased muscle activity. This in turn has an effect on myofascial pain, which TMD patients perceive more strongly (Yemm 1976). It is precisely this spiral of chronic pain and stress that often leads to catastrophising behaviour.

Risk factors for TMD include muscle hyperactivity, stress, anxiety, (physical) trauma, depression, stressful life events and vulnerable personality types. Since, as mentioned above, the disease affects women more often than men, the biological female gender is also one of the contributing risk factors. (Zakrzewska 2002).

Thus, it can be concluded that both physical dispositions and negative emotions can influence the perception of pain in TMD patients. Finally, however, it should be mentioned that pain in the head region is of particular psychological importance, as the face is essential for interpersonal encounters, communication and self-confidence (Dionne et al. 2009).

Figure 10: Pain posture for facial discomfort [9]

2.2.3 Diagnostics and therapeutic approaches

The previous description should have made it clear how difficult it is for medical professionals to arrive at an exact diagnosis of TMD or to treat the symptoms in a targeted manner. Because pain in the facial region cannot always be precisely assigned to a disease, both the diagnosis and the treatment options are challenging. It is therefore not uncommon for patients suffering from facial pain to receive several diagnoses (Wright 2010).

Examination methods usually include palpation, radiography, arthroscopy and magnetic resonance. The American Dental Association recommends only conservative treatment methods for temporomandibular dysfunction (Griffiths 1983). Not enough is known about the effectiveness of surgery. Antidepressants and psychological care are considered common measures (Zawreska 2002). But targeted physiotherapy can also sometimes bring relief from the symptoms. According to Medlicott & Harris (2006), active exercises and manual mobilisation in the course of physiotherapeutic intervention often lead to an improvement.

---

[9] Source Figure 10: Self-taken photo of model Nadine Rosenberger

However, in order to achieve the best possible therapeutic outcome for the patient, cooperation between several professional fields would be desirable (Neff 2003).

According to a qualitative study by Mohr et al. on pain experiences in chronic facial pain (2011), there is increased dissatisfaction and suffering on the part of patients, as well as a problematic doctor-patient relationship, which further complicates treatment measures. Those affected suffer particularly from their situation, as the pain they perceive as physical often deviates from the condition described in their medical report (Neff et al. 2003). Since psychogenic factors are also considered one of the possible causes, patients sometimes feel that they are not taken seriously enough. In the study by Lennon et al. (1989), for example, more than half of the 151 participants were told that they were just imagining the pain. The patients, however, perceive the pain as a physical symptom and therefore look for satisfactory diagnoses that explain their complaints (Kotarba 1983), as well as for effective treatment options that relieve them of their pain.

Often, however, they reach a limit and their attempts remain unsuccessful. This leads to more frequent changes of doctors on the one hand and a lack of trust on the other. This mechanism makes patients so vulnerable to stigmatisation, which will be explained in more detail in the following chapter.

3 Stigmatisation

3.1 Clarification of terms

Stigmatisation is a complex process of social interaction between a 'normal', unmarked person and a person who has an evidential or perceived 'mark'. Such a 'mark' defines that person as defective, imperfect or undesirable. The mark can be physical, such as being outwardly disfigured, or attributed on the basis of behaviour, origin, biography and group membership (Jones et al. 1984).

People with such a "mark" are often given less respect because they evoke negative reactions in people in specific situations (Goffman 1963). In addition, the process of stigmatisation is accompanied by stereotyping. This means that generalisations of personality traits are made on the basis of very superficial information. Thus, there is a tendency to impute a multitude of other deficiencies to the person in whom a weakness is discovered (Goffman 1963).

3.2 The stigma vulnerability of TMD

In their study on the stigma of chronic facial pain, Lennon, Link, Marbach and Dohrenwend (1989) found that the majority of participants felt alienated and misunderstood because of their pain. According to the study, the perception of stigma among sufferers arises on the one hand from the number of different doctors consulted, and on the other hand from the fact that patients are often told by these doctors that their pain is merely imaginary. The fact that the symptoms of temporomandibular dysfunction cannot be explained biomedically and are therefore often considered to be psychogenic adds to the potential for stigmatisation. The perception of such labelling can lead to an impairment of social relationships, which is discussed in the following chapter.

First, however, the problem of stigmatisation should be addressed. In order to understand both sides - patients and doctors - it is necessary to illustrate why it is obvious for medical professionals to attribute the symptoms of temporomandibular dysfunction to psychological reasons. The dilemma is then considered from the patient's perspective to illustrate the challenges they face. Finally, sources of stigma are cited in this context.

3.2.1 Who seeks clinical treatment and why

Pain is a subjective experience that is perceived differently by each individual. This fact makes it difficult to categorise pain in a generalised way. After all, it is impossible to check how excruciating one and the same symptom is for two different people. What has been found in studies, however, is that not all sufferers of temporomandibular dysfunction feel equally affected by their pain. Considering the fact that TMD occurs in different forms - as already explained in the previous chapter - it seems plausible that the pain perception of the individual symptoms is different for each person.

Nevertheless, a study by Marbach and Lipton (1978) showed that the illness behaviour of people with TMD/facial pain also depends on psychosocial and sociodemographic factors - i.e. aspects that are not directly related to the physical signals of the body. The fact that only a small percentage of TMD sufferers seek treatment, while a much larger percentage do not feel the need, raises the question of which people seek medical help. Marbach and Lipton examined patients at a TMJ clinic at Columbia University School of Dental and Oral Surgery for socio-cultural backgrounds. They found that the socio-demographic and socio-cultural profiles of patients seeking treatment differed significantly from those of non-patients in another study.

Sociocultural variables aside, people with temporomandibular disorder who are under greater stress are more likely to seek treatment. This can be explained by the fact that seeking treatment distracts from the actual psychosocial problem causing the person's stress. Focusing on pain management is perceived as less threatening than confronting the problematic life situation (Marbach et al.). Thus, to escape the personal stress of their home life, people with facial pain turn to their physical signals rather than confronting the dissatisfaction about their life situation. The symptoms provide both an opportunity and an excuse to escape from the private difficulties (Marbach & Lipton 1978).

For example, in the study at Columbia University School's TMJ Clinic, 62% of those examined reported that their symptoms first appeared after a serious life event (Marbach & Lipton 1978). Based on another study by Molin et al. (1973), it is known that such critical life events often result in depression and anxiety, which in turn affect pain tolerance and lead people to seek out clinics.

To what extent these people then admit that there is a connection between their perceived physical pain and the drastic life event depends in turn on the environment in which they grew up. Here we return to the socio-demographic study by Marbach and Lipton (1978):

If it has been tolerated that one expresses emotional problems, it is generally easier for the patient to express this and to accept a possible psychological explanation by the health professional. If the patient has a socio-cultural background in which an expression of emotional distress was undesirable, such an interpretation by the doctor of his/her facial pain is irritating and anxiety-provoking and weakens the doctor-patient relationship (Marbach & Lipton 1978).

As already explained, the jaw and mouth area is closely connected with interpersonal and emotional aspects and is thus a suitable projection surface for psychological conflicts (Sandler & Dare 1970). Due to this, the localisation of pain in the jaw has a high symbolic significance, as (unresolved) psychological conflicts can be expressed here on a somatic level (Barsky & Klerman 1983).

This may be one possible explanation why some patients with facial pain do not respond to conventional therapies, especially since the actual problem is to be found elsewhere. If the circumstances of the patient's life are not taken into account when the findings are recorded, this can lead to the patient not improving despite clinical treatment.

In summary, it can be said that besides physical factors, both psychological and socio-epidemiological aspects are decisive for whether people with TMD symptoms seek medical care or not. However, this finding runs the risk of fundamentally questioning the pain experienced by patients. It must be mentioned here that the participants in the study by Marbach & Lipton (1978) are not representative of all sufferers, especially since those for whom therapeutic interventions are effective are excluded. Finally, patients were deliberately selected who had already been treated by at least 3 different doctors (dentist/specialist/ ENT/orthopaedist/surgeon) and who had experienced pain over a period of at least 6 months. In order to establish a general profile for facial pain patients, further measurements would have to be carried out in other sociographic areas.

The reasons described above serve at best to explain why medical personnel are tempted to look for the problem of TMD patients in psychological factors. This leads directly to the sources of the stigma of temporomandibular dysfunction.

3.3 Sources of stigma in chronic facial pain

3.3.1 The inexplicability of TMD pain

According to the article "Losing/Saving Face - Sources of Stigma (...)", also published by Marbach, Lennon, Link and Dohrenwend (1990), a major reason why TMD patients may perceive stigma is the unknown cause of TMD. The unexplained pathogenesis complicates medical management and therefore in many cases leads to doctors saying that patients exaggerate, simulate or even imagine the pain (Lennon et al. 1989). This can lead to pejorative labelling, which is the next source of danger.

3.3.2 Clinical labelling

Since doctors do not have a biomedical explanation for the pain of those seeking help, they often attribute the cause to psychological reasons. This can be extremely frustrating for the sufferer as they feel as if they are being blamed for their suffering (Lennon et al. 1989).

The term "psychogenic" is already a kind of "label" that implies that the sufferer has caused the pain themselves. It gives the impression that they should be able to control the pain themselves if they did not fail to do so because of personal weaknesses (Lennon et al. 1989). However, TMD patients experience pain as something beyond their control. Therefore, psychological explanations are useless and pejorative to them (Lennon et al. 1989). A young woman with TMD commented on this in a mail survey by Marbach and Lipton (1987) as follows (translated from English):

> *"I'm only 21 years old and I've already been to more than 30 doctors, half of whom have told me in so many ways that I'm 'crazy'."*

For the patients, their pain is a problem of the body and not of the psyche (Kotarba 1983). Many patients therefore reject the psychogenic explanation and search for other explanations that are more coherent for them. According to Marbach and Lipton (1987), patients with pain in their health often feel tense during consultations with doctors. Doctors are authority figures for patients. If TMD sufferers receive disdainful explanations from such powerful people as they are, the interaction can be considered tense (Salter et al. 1983). This often results in a difficult doctor-patient relationship and disturbed communication between the two parties.

Mohr, Von Piekartz and Hotze (2011) conducted qualitative interviews on this at the Osnabrück University of Applied Sciences in their study on pain experience and pain behaviour in chronic facial pain. The evaluation showed that both the lack of information about the pain on the part of the doctors and the lack of interdisciplinary communication between the individual professional groups make the cooperation between doctor and patient more difficult. This also impairs the course of therapy. What was striking in the interviews was the different reasons given by the test persons for the poor course of the disease. Some of them looked for the fault in themselves:

> *"Well, you also have negative experiences, for which I am probably 50% or maybe 70% responsible myself! Because I'm a person who doesn't really dare to say how bad things are for me. So I've always come to an agreement with myself, so I couldn't expect the doctors to perceive it the way I did.*

Others attributed the chronicity and severity of their orofacial pain to medical treatment:

> *"Once you've screwed that up, [...] and then you're on your own! And*
> *I mean, I'm not afraid of doctors on the whole! (Crying). Yes, you just want to get help, you want the pain gone! [...]"*

Some of the interview participants also felt that their pain would have remained less severe if they had been referred more quickly to a specialised service.

> *"If I had received faster help, whether I would really have been*
> *would have had to dive so deeply into this world of pain?"*

The participants in the study by Mohr, Von Piekartz and Hotze (2011) also stated that they did not feel taken seriously by the medical staff.

> *"According to the motto, the woman is crazy, she only dreamed it all! I probably made it all up myself, I probably ground my teeth down myself! (laughs). [...] And then I think, why doesn't an ENT doctor recognise the connection [...] He says he can't imagine it. [...] Yes, and then he writes to the health insurance company that I object to the medical diagnosis and that I could not be treated!"*

Respondents in another study also spoke about dissatisfaction with the health system. They reported that they were not listened to carefully and that they had the impression that their complaints were a very annoying problem for doctors. They complained about delayed diagnoses, rejection and disinterest on the part of the medical profession. These components were among the reasons why they felt insufficiently supported and abandoned (Hazaveh & Hovey 2018).

If you analyse the statements of those affected, you can hear both the surrender and the struggle. It is reminiscent of a kind of inner conflict. Patients are divided between the desire to change their situation in the sense of an improvement in their state of health and at the same time the frustration that none of their attempts brings them closer to this desire. It seems like an eternal struggle that is put up with even though the goal seems hopeless. This futile endeavour is in tension with the acceptance of submitting to pain.

Hazaveh & Hovey (2018) pointed out that this uncertainty that patients find themselves in, together with the persistent symptoms, adversely affect every aspect of their daily lives. Sufferers are literally up in the air. In English, the people conducting the study referred to this state as "limbo". If the expression is translated literally into German, it also means something like "limbo", "limbo", or "imprisonment".

This is what one of her subjects had to say about it (translated from English):

> *"It was 9 months... It took me 9 months to get an appointment there [specialist clinic] and finally find out that I was suffering from this and not that... (deep breath) we tried so many many many medicines... Unbelievable... I stopped counting (laughter). And I've been living with it for... I mean, it's not that bad, but I'm really struggling 24 hours a day."*

The patients' desire for a diagnosis that confirms their physical discomfort and to find a suitable form of treatment is so great that they visit one doctor after another. Pejorative labelling thus leads to so-called "doctor hopping", which can also be the next cause of stigmatisation.

3.3.3 Excessive search for medical help

The interpretation that their pain is only in their head creates a desire in many sufferers to convince others that their pain is actually real. However, the extensive search for medical help can itself be the source of stigma if it is unsuccessful (Lennon et al. 1989).

The fact that people accept clinical treatment outwardly shows in principle an interest in wanting to get well again (Parsons 1951). Sufferers are anxious to find out the cause of their pain and to do something about it. However, if treatment attempts repeatedly fail, which is usually the case with TMD, this is often interpreted as weakness on the part of the patient. This can lead to the environment doubting that the patient is really willing to get better. The original motivation of the patient to prove the pain in order to escape stigmatisation can ironically lead to the opposite effect, namely that they feel stigmatised (Lennon et al. 1989).

One participant in the study (Lennon et al. 1989) described this experience as follows (translated from English):

> *"I now had a realistic goal, which was to find the cause of my pain and get rid of it. I also had a personal ulterior motive. I had to prove that I was not 'crazy'. But it only led to a repetition of the pattern. This happened because a number of other doctors I went to, worked with me for a period of time, eventually got frustrated and came to the conclusion that my problem was psychosomatic, not physiological."*

Thus, the more intense the patients' search for explanations of their symptoms, the higher the probability of encountering pejorative labelling, as well as experiencing treatment failures (Lennon et al. 1989). This search behaviour thus contributes to stigmatisation. The longer the medical record, the higher the vulnerability to stigma. Patients want validation of their physical suffering, but the more they seek it, the greater the risk of feeling stigmatised. A vicious circle ensues.

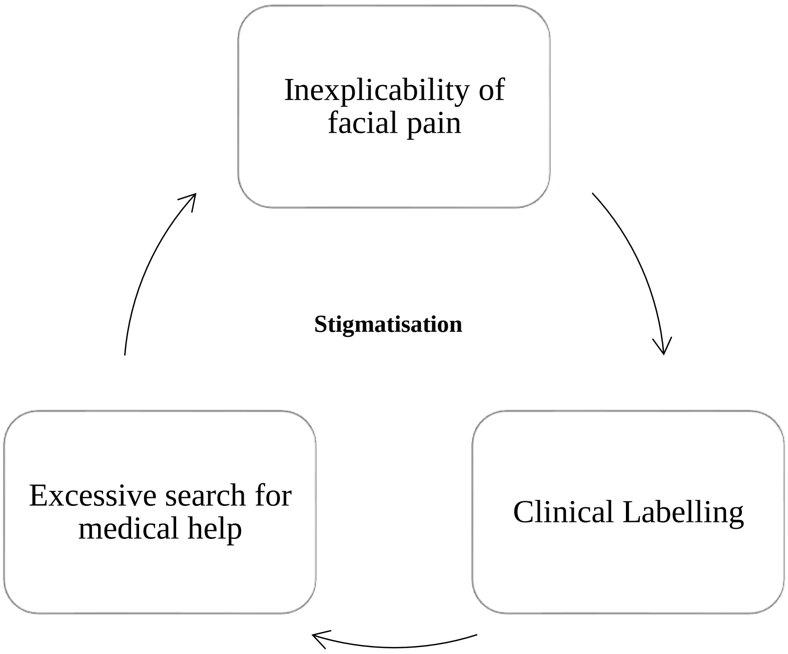


Figure 11: The emergence of the stigma of chronic facial pain

In the study by Lennon at el. (1989), patients also began to question their own mental health over time. These self-doubts were connected with the fear that the labels "malingerer" or "hypochondriac" might be justified after all.

(translated from English):

> *"I went to six different doctors. None of them found out what was wrong with me. I became very depressed and withdrawn... Everyone told me I needed a psychiatrist. I started to believe them."*

Whether or not patients accept their doctors' psychological interpretations, such interpretations, if heard more often, can make them feel stigmatised, misunderstood and frustrated (Lennon et al. 1989). Over time, they develop the views that others believe their suffering is due to their own character weakness or flaws in their personality. They thus feel stigmatised. Marbach et al. (1990) further suggested in their study "Losing/Saving face" that the perception of stigma and the associated low self-esteem, hopelessness and helplessness could even lead to a change in immune function. More studies would have to be done on this, however. What is already proven, however, is that patients with orofacial dysfunction often feel alienated, devalued and separated from others as a result of stigma. The extent to which stigma can therefore also affect social relationships and the quality of life in general of those affected by it will be explained in the next chapter.

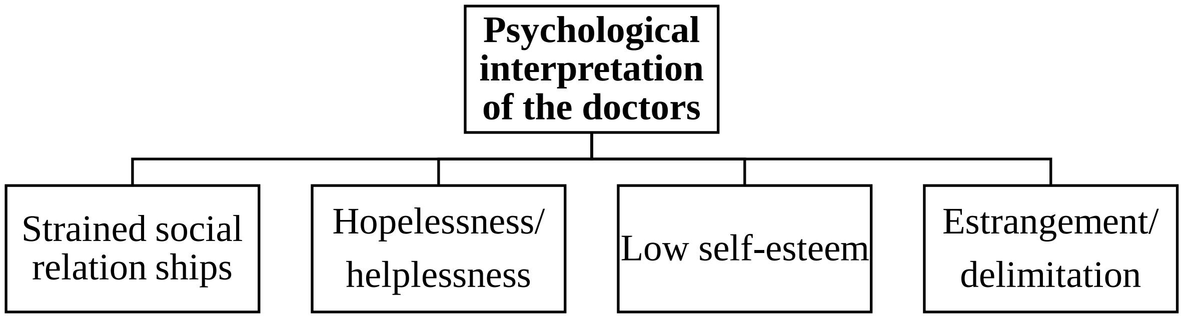


Figure 12: Possible consequences of a psychological interpretation of the medical profession

4 (Social) life, loss and loneliness of chronically ill people

The following chapter will provide an insight into the changed conditions under which people manage their lives with chronic facial pain. In particular, the poor social life of the persons is examined and the extent to which relationships are strained under the circumstances of temporomandibular dysfunction and its accompanying symptoms is described. At the same time, the possibilities of the patients to deal with their restriction in their circle of acquaintances are discussed. It will also be made clear to what extent clinical and social stigmatisation plays a role for TMD patients in this context. A final section on illness-related losses in the lives of the chronically ill in general will illustrate why physical and psychological burdens are associated with a lower quality of life and often lead to self-esteem crises (Hazaveh & Hovey 2018; Charmaz 1983).

4.1 Influence of stigmatisation on social relationships

TMD patients who experience their condition as stigmatising are not only at risk of negative labelling by medical professionals, but also of possible rejection by those around them who take notice of their condition. After all, patients are not detached from their social environment. The question now is how they deal with their illness in public and in their private lives. Lennon et al. (1989) showed in their study "The Stigma of Chronic Facial Pain and It's Impact on Social Relationships" that stigmatisation in the health context can also have consequences for social relationships. They found that the quality of social relationships can be negatively affected due to several factors.

4.1.1 Stigma management strategies

Of course, patients want to escape negative evaluation by their fellow human beings as much as possible. Thus, it is up to them to decide how to deal with their pain experience and treatment attempts externally. Lennon et al. (1989) have argued that there are two common strategies for dealing with TMD in the social context. Either one keeps the treatment attempts secret from others, or one discloses it to them with the intention of informing outsiders about it in more detail. The attempt to educate others is accompanied by the hope of being understood by them (Lennon et al. 1989).

However, both methods - disclosure and secrecy - are no guarantee that the sufferers will not feel alienated anyway. Lennon et al. (1989) see one reason in the invisibility of the pain. This does mean that the orofacial disorder can be easily hidden from others, especially since there are no striking visual clues in the external appearance (as is the case, for example, with obesity, amputations, facial paralysis, skin rashes). However, keeping pain a secret can also be very exclusionary. A study on epilepsy, for example, has shown that simply "passing" - that is, silently walking past other people - can be isolating because the sufferers secretly know that they are different from the others (Schneider & Conrad 1986).

If, on the other hand, you choose to disclose your condition and your search for effective treatments, you risk being disappointed or misunderstood by others. Outsiders can never fully understand the extent of the suffering. The fact that orofacial pain is not visible to others also makes it difficult to communicate (Wolf et al. 2008). The participants in the above-mentioned study stated that their acquaintances had the impression that they did not suffer any pain at all, or that they were healthy and intact anyway. The central factor here is that patients are often not believed because there are no outward signs of illness (Hazaveh & Hovey 2018):

(translated from English):

> *"Sometimes it's so frustrating... So frustrating because people can't see that I'm sick. They look at me and think I look fine. I don't like it when people think I'm just pretending to be sick."*

However, if sufferers tell their friends about their futile search for medical care, or even complain about the pain, they risk being labelled as hypochondriacs - or worse, they are outwardly seen as unable to manage their pain because all treatments fail (Lennon et al. 1989).

This is the story of a TMD sufferer in the Stigma study who underwent unsuccessful jaw surgery (translated from English):

> *"I was so embarrassed to tell the others because how do you tell someone you had an operation but it didn't work."*

(Note by Lennon et al. (1989): This patient never went to see her surgeon again, otherwise she would have had to tell him that the operation had not relieved her pain. She describes it as follows: *"I was afraid he would then say that I had imagined all this pain."*

4.1.2 Pain-related isolation & loneliness

If you are in pain, it also affects your enjoyment of life. So it is understandable that people who suffer from severe pain often have no interest in things that otherwise bring happiness to others. This especially includes aspects of social life. Activities with friends lose their appeal, the circle of acquaintances is neglected, encounters with other people in public are unpleasant. Pain medication is not a permanent solution for the patients. Subjects of the study by Hazaveh & Hovey (2018) explained that taking tablets permanently would not be beneficial because the medication made them so slow.

However, the poor physical condition significantly affects the persons' daily life and thus also hinders their participation in social life. Since the intensity of facial pain can vary, it is usually unpredictable (Lennon et al. 1989). Therefore, the pain often leads to social withdrawal. As a result, many sufferers experience a feeling of social exclusion. Those affected feel excluded from society and no longer part of their circle of friends. The lack of a sense of belonging and the belief that they are completely alone with their problems causes loneliness. Facial pain patients often do not want to communicate their suffering to the outside world, but then feel misunderstood precisely because of this. Subjects of the study by Mohr et al. (2011) attribute the feeling of exclusion even to a low level of sympathy from the social environment:

> *"No, [...] people don't like to talk about it, because many don't know it either! [...] They can't understand it either, they simply don't understand it!*

The lack of interest is often interpreted by the patients as a rejection of their own person:

> *"It's best not to say anything at all! [...] No, not because it hurts, but because people don't want to hear it any more. And people don't like to talk about it any more."*

In another phenomenological study, one person reported voluntarily foregoing the support of their friends and deliberately not involving them in their pain experience (Hazaveh & Hovey 2018):

(translated from English):

> *"I mean, some of my friends are helpful, but I don't want to talk about my pain all the time. The whole point of seeing your friends is to do something different. I think I*

> *have a good support network around me, but I think it's because I never talk about my pain. I'm not sure if they would still stand by me if I talked about my pain."*

Interpersonal interactions are often avoided because of the increasing fear of rejection. Hazaveh & Hovey (2018) see a decisive aspect for this in the disbelief that the social environment often has towards the person with the illness. In the above-mentioned study, the test persons told us that they were met with scepticism from their friends or that even close family members doubted their pain. They saw the problem in the fact that it was difficult for people around them to understand their suffering, as they had never suffered from such pain themselves (Hazaveh & Hovey 2018). The sufferers, in turn, perceive this as a lack of understanding and feel judged. They feel the need to justify their complaints. In this context, the patients in the study also spoke of an aggravation of their suffering when they had to explain their illness to others.

(translated from English):

> *"The worst thing about having to live with this disease is when people look at me with this certain incredulity. I hate it when others judge me. When you have cancer, you get so much empathy, but with my disease, nobody seems to care. I mean, just because I don't have any visible signs of illness doesn't mean I'm not sick."*

If the fear of being misunderstood prevails, people keep their orofacial pain to themselves. However, this strategy further separates sufferers from their loved ones. Respondents commented on this as follows (Hazaveh & Hovey 2018):

(translated from English):

> *"I mean of course it means that there are activities that I can't do and that sometimes I have to cancel friends and I'm not sure that people always understand and realise that it's not because I'm unreliable, it's because sometimes I'm not well. But instead of telling people I'm in pain, I just make up excuses."*

For some affected people, it also seems safer to withdraw completely from their social network. They prefer to be alone and voluntarily choose isolation. In her article "Loss of self: a fundamental form of suffering in the chronically ill", the American sociologist Kathy Charmaz referred to the social conditions that make it difficult for chronically ill people to lead a "normal" life. She sees the reason mainly in the fact that those affected do not question these social concepts, but simply accept them as a given. The world is a place constituted for healthy and active people. People with chronic illnesses or physical impairments measure themselves against the standards that apply only to "healthy" people and at the same time feel the need to withdraw from this world that is made only for the "healthy". Charmaz concludes that the sick people therefore restrict their own lives more than they should. They participate less and less in life, actually doing this for their own protection, but in reality forego many beautiful things worth living for. Moreover, this withdrawal is at the expense of their self-image, which is increasingly lost (Charmaz 1983). This will be discussed in the following chapter.

According to Charmaz's study, the fact that patients spend a large part of their time on medical therapies further reinforces isolation. They are isolated from others and focus all their attention back on themselves. This in turn makes them feel lonely.

According to Mohr et al. (2011), if patients do engage in social activities from time to time in order to maintain their social status, this results in an outward suppression of pain. The participants accept a worsening of their condition for social activities, although they are already aware in advance that their complaints are worse afterwards:

> *"Yes, I'll do something then. But you're right, yes, there is a certain fear. But I know it too. If I do this or that, you'll be in more pain again! But I do it from time to time, because I don't want to live in total isolation.*

Because the pain in the oro- and craniofacial area functionally impedes both speech and facial expression, according to Mohr et al. (2011), verbal and non-verbal communication is also impaired. All but one of the participants in the qualitative interviews emphasised the altered speech, but also facial structure in mimic expressions. Some patients even stated that they avoided verbal communication because of the pain (Mohr et al. 2011).

4.1.3 Dissatisfaction in social relationships

Now it is obvious that challenges in dealing with the stigmatised disease may not only occur in the closer environment, but also in the closer (family) circle or in living together with other persons. In this respect, Lennon et al. (1989) have proven a connection between dissatisfaction in intimate relationships and alienation due to the pain experience.

For example, in their study, out of 151 participants, those who lived with a boyfriend, or were married and in a lot of pain, and felt alienated to a high degree, were very dissatisfied with the relationship.

Single patients who had high levels of alienation were also dissatisfied with their relationship life, regardless of the level of pain. Similarly, singles were found to have a correlation between the stigma management strategy of "disclosure" and dissatisfaction in their social life. This means that those single female patients in the study who told others about their pain experience and their efforts to seek effective therapies tended to be more dissatisfied in intimate relationships. They would always be at risk of rejection if they disclosed their illness story to potential partners (Lennon et al. 1989).

As far as support in living together is concerned, it was found in the study that alienated female patients counted more on the help of household members than less alienated ones (Lennon et al. 1989). That stigmatised persons are more likely to trust close relatives than people outside their household was assumed by the authors before conducting the study for the following reason:

Relationship partners who are very close to the ill person experience the gruelling search for treatment first-hand and are also more knowledgeable about the many facets of pain than people outside the household with whom the ill person has only superficial contact. Thus, the authors of the study assumed that the sufferer would not risk rejection or negative reactions from others who only witnessed part of it (Lennon et al. 1989).

Even though cohesion is greater in intimate bonds, the relationship is nevertheless subjected to a great test of endurance, which is burdensome for both parties involved. Hilbert (1984) writes about this (translated from English):

> *"Nevertheless, this dependence on those who are initiated is potentially burdensome for both - sufferers and their supporters, because no matter how close others may be to you, they cannot relieve you of the pain and certainly cannot empathise with it in its entirety. "*

4.2 Quality of life of chronically ill people

Living with chronic pain is a daily challenge. People who suffer from it have to manage their entire daily routine under adverse circumstances. According to Wolft et al. (2008), it is already exhausting for those affected to muster enough strength for hygienic routines, even to get out of bed in the morning. Domestic duties often have to be neglected due to pain, and external help has to be sought. It is not uncommon to give up one's job, but also favourite pastimes that one used to enjoy. Since the physical condition depends on the day and cannot be calculated, chronically ill people also find it difficult to plan ahead (Wolf et al. 2008). Long rest periods before or after activities have to be taken into account. The persistent pain prevents people from leading an intact social life and from pursuing their goals and dreams. Resignation and passivity are often the result (Wolf et al. 2008). Social withdrawal occurs, often associated with depression, disillusionment and a strong sense of hopelessness.

In the previous chapters, the impact of stigma on the social life of TMD patients was discussed. In the next points, health-related quality of life will be discussed in more detail and the factors that affect it will be described. Aspects of permanent pain and its influence on the way of life as well as the mindset of facial pain patients will be examined.

4.2.1 Disillusionment

Pain is an emotional state that humans naturally want to avoid. When it occurs, it attracts the full attention of the person experiencing it. It causes discomfort and unease. As a logical consequence, the person wants to free himself from this state. It is a natural human need to be free of pain. If this does not succeed over a longer period of time, disappointment and frustration usually result. Many people become disillusioned and desperate.

A key contributing factor to the disillusionment of chronically ill people is the perceived hopelessness. Many patients with orofacial pain describe this feeling as if they were trapped by the pain or as if the pain was a kind of punishment (Wolf et al. 2008). This hopelessness in turn often leads to resignation and frustration. The hope for an improvement of the complaints or for a better life in general becomes weaker. The belief in getting well is often even abandoned altogether. A resigned attitude is especially noticeable with regard to the future. In the study by Wolf et al. (2008), when patients were asked about the future, they immediately changed the subject or ignored the question. Statements in this regard were basically negative-

(translated from English):

> *"There is no future for me, that much I understand."*

In the study by Wolf et al. (2008), pain itself was found to be an all-encompassing phenomenon. It plays the dominant role in the patients' everyday life and has the greatest power over their entire life. Their lives are determined by pain (translated from English):

> *"I have no other problems in my life, not a single one. No, absolutely not. I don't. The pain is my problem. Mm."*

In the qualitative interviews by Mohr et al. (2011), all patients without exception stated that their lives had changed abruptly with the onset of pain and that since then their entire lives have been focused on pain. They also all reported that their goals in life had changed due to the orofacial pain.

> *"Without the pain, I would live very differently! [...] Because everything I do is different from how I would otherwise do it if I were healthy!" (cries)."*

In addition, a change in behaviour with regard to destructive actions was noticed due to the permanent pain in the face. For example, one person was indifferent to swallowing strong tablets although she knew that she was not actually allowed to take them because of an intolerance (Wolf et al. 2008). She commented on this as follows (translated from English):

> *"I thought, `I don't care. Then I'll just have to die."*

4.2.2 Losses

In their phenomenological study (2018), Hazaveh & Hovey documented that people with orofacial pain usually experience various forms of loss. Four main types emerged: loss of job, loss of identity, inability to experience pleasure in eating, and loss of pleasure in participating in social activities. The last two points seem plausible, especially since it has already been discussed several times why the social life of pain sufferers changes for the worse during the illness. The inability to enjoy food is also unsurprising, as the pain occurs in the jaw region and is particularly intense with mechanical stress. Thus, the next paragraphs of this paper are devoted to the first two forms: Loss of job and loss of identity.

Job loss

When the pain and its consequences bring patients to the point where they have to give up their jobs due to illness, this can be problematic in many ways. Quitting one's job always means a change in financial terms. Thus, many chronic pain patients are exposed to a great burden. On the one hand, this arises from the fact that giving up a job at the same time brings a change in the household budget, which in turn affects the standard of living in most cases. On the other hand, many cost-intensive treatments are not covered by health insurance and must therefore be paid for privately. According to statements by some facial pain patients in the study by Mohr et al. (2011), in some cases inappropriate therapies were carried out that were unnecessary and led to high expenses. The patients were under great financial pressure.

> *"And cost a fortune to boot! Really! [...] And the suitable therapists here in town, they're all private! (Angry). Or over nine months waiting time for patients with health insurance. I can't wait with that!"*

Apart from the financial and existential importance of the profession, the tasks and duties it entailed suddenly disappear from people's lives. The feeling of being effective, significant and useful is missing. Recognition for achievements and a sense of achievement in the professional sphere are absent. Many persons feel this as a great loss and suffer from it. In Hazaveh & Hovey's (2018) study, some subjects claimed to be unable to recognise themselves in this context. They had difficulty identifying with the person they were before the pain:

(translated from English):

> *"My illness has really changed how I think about myself. When the pain flares up, I feel so weak and helpless. I used to be a very confident person, but now I just feel useless and I'm so sad about having to give up my job. I mean, I've sort of accepted that I can't work anymore, but now that I'm not working, even more so I can't do much around the house because I feel permanently tired and in pain. I really miss my old life and the person I used to be."*

Loss of self-identity

Kathy Charmaz, the American sociologist, has dealt extensively with the loss of the self of chronically ill people. In this context, she describes that this kind of loss depends primarily on the values through which the self-image is formed. In societies and worldviews where self-worth is linked to hard work, achievement or responsibility, for example, sick people question their own value as soon as they can no longer live up to these principles. If one gets an illness, however, these factors are precisely the first to disappear. People lose both conscious control over their lives and their own ability to take action.

If they are not able to live a "normal" life that corresponds to the ideals on which their self-image is based, their self begins to crumble (Charmaz 1983). They blame themselves and think badly of themselves. Not only does self-esteem gradually decline, but self-images dissolve without developing equivalent new ones. In other words, they lose themselves (Charmaz 1983).

Charmaz sees the causes of the loss of self-identity in the restricted lifestyle. The everyday life of chronically ill people is interrupted by doctor's appointments, medical treatments and riddled with recurring periods of pain. People can no longer do what they once did. Often they can no longer pursue their personal interests or pursue their own goals. When much of what once defined one's self falls away, the identity one thought one had is significantly shaken and the image of oneself is forced to change. Moreover, being tied to medical procedures reminds people especially of this limited freedom and makes them aware of their own lack of independence. Some patients (for example dialysis patients) had the impression that the treatments dominated their lives (Strauss & Glaser 1975). This immense dependence on external treatment measures is constant evidence of the loss of control over one's own life and eventually leads to the loss of one's self (Charmaz 1983). The patients experience themselves as passive, powerless and surrendered to fate.

Another origin of negative self-perception, according to Kathy Charmaz, is the mirroring of other people's behaviour. This means that all behaviour of other people is related to oneself. Since chronically ill people often minimise their social contacts, interpersonal interactions rarely occur. According to Charmaz, a routine check-up with the doctor is therefore already a special event for many chronically ill people. It seems obvious that the doctor-patient relationship thus has an extraordinary importance for the self-esteem of pain sufferers. How those affected think about themselves depends very much on how they are treated. Statements and manners of the medical professional form the basis for their self-assessment, especially since there are few opportunities for contact with other people. If the patients are taken seriously by medical professionals, a positive reflection occurs. In this case, it is easier for the patients to maintain a better image of themselves. However, if the doctors - the very people who have a particularly high value for them - do not believe them or doubt their statements, even the shortest encounters can lead to questioning and deep shocks of one's own self (Charmaz 1983).

One doctor had the following to say about it:

(translated from English):

> *"They can take my most casual, thoughtless remark or suggestion for absolute power and as a direct reflection of themselves."*

However, self-reflection and mirroring take place not only in encounters with people from the health sector, but also with those from the family circle. Here, too, tensions can arise. Relationships of chronically ill people are often full of conflicts due to the aggravating factors of illness and contribute to negative self-concepts. Thus, it is not always the social loneliness caused by the minimal contact with the outside world that troubles the ill person, but often the emotional loneliness experienced. People with pain often feel alone and misunderstood, even though they have enough people around them who care about them. This happens, among other things, because decisions are made about them in certain situations or they are treated as if they were a "problem" in logistical considerations, for example. In order to maintain the status as an "equal" person and also to be perceived as such, they have to fight constantly (Charmaz 1983).

In addition, the sufferers suffer from burdening those close to them. They are dependent on them, depend on their support and feel useless. They feel ashamed of being a burden to others. This also ultimately has a negative effect on what they think of themselves (Charmaz 1983).

It also happens that ill persons are discredited by family members because they do not fulfil their expectations due to the limitation caused by the illness (Charmaz 1983). This creates disappointment on both sides. At times when the pain sufferers actually need the most support and understanding from their loved ones, they in turn do not feel valued enough by them. The relatives may perceive it as inattentive if the ill person does not respond to their needs or no longer takes over tasks for which they used to be responsible. The relatives interpret this as a kind of indifference towards them. If the ill person does not carry out the role they had, they are often put under pressure by others. They are expected and demanded to "function" again as they used to. Since this is almost impossible in most cases, relatives sometimes doubt the motivation of those around them and accuse them of using pain or fatigue as an excuse not to fulfil their obligations.

Parade allegations from Charmaz's (1983) qualitative study are:

(translated from English):

> *"You don't do enough; you don't try hard enough; you use it as an excuse. "*

Such accusations can be very hurtful to chronically ill people and reinforce negative self-images.

Here is a graphic overview of the individual categories that can cause the original self-image to disintegrate in chronically ill people:

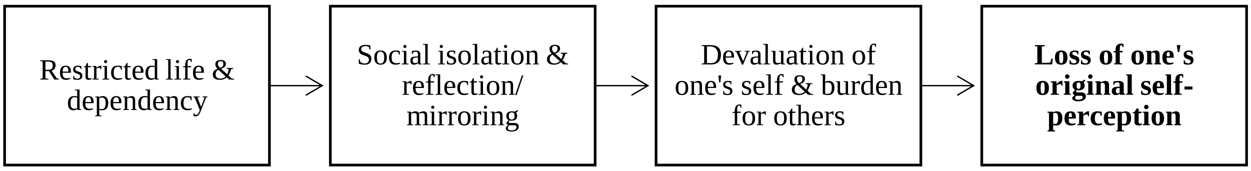


Figure 13: Factors for the loss of one's identity with a chronic illness

However, there is also the opposite phenomenon in social relationships. Relatives are often already well aware of the facets of their loved one's pain and in certain situations can even interpret external signs better than those affected themselves. If close people notice alarming signals in their loved ones, they can warn them in advance and thus protect them from worsening their complaints. In Charmaz's study, a young woman stated that her mother was more alert in public than she was and had often saved her from embarrassing situations in which she no longer had control over her body (Charmaz 1983).

The last aspect of Charmaz's article seems particularly tragic: Regardless of the social interaction with other people, sometimes the biggest problem for the devaluation of one's own person is the sufferers themselves. Sometimes the self-concept crumbles not so much because of the unfulfilled expectations of others, but because the sick person does not live up to his or her own expectations, which are often even higher than those of others (Charmaz 1983). If chronically ill people do not manage to do everything the way they were used to doing it in the past, they tend to blame themselves grossly. They compare themselves with their former standards of performance and then feel bad when they no longer achieve them (Charmaz 1983). Self-accusation and strong feelings of guilt ensue. Pain sufferers think of themselves as failures and condemn themselves for their failures. According to Kathy Charmaz, they tend to apologise to others for their inadequacy and paucity. They do this out of the belief that they would not be a complete person until they were fully "functioning". In this way, they subsequently apologise for their existence and thus contribute to their own devaluation as a human being (Charmaz 1983).

All in all, it can be stated that chronically ill people are exposed to a strong pressure of suffering. They not only have to cope with the persistent physical discomfort, but also with the psychosocial side effects in their everyday lives. Emotional and social loneliness, as well as isolation and withdrawal from active life, make the world of those with the disease smaller and smaller. Financial problems are compounded by the loss of enjoyment of social activities and culinary pleasures, negative self-perception and the dissolution of positive self-images, to the point of questioning one's own identity and worth as a human being.

Lack of compassion from those close to them causes the sufferer deep distress (Hazaveh & Hovey 2018). Facial pain patients in particular experience alienation due to the pain. The invisible, unexplained symptoms isolate sufferers and create feelings of stigma. TMD patients who seek treatment often suffer from disillusionment and helplessness due to the difficult-to-treat pain. The disease is very often accompanied by a significantly lower quality of life and usually has a negative impact on social relationships.

The information in this theoretical section was largely based on studies that examined patients with temporomandibular disorders, as Eagle's syndrome is very unknown and there is little scientific material on it to date. Because the location of pain in Eagle's syndrome is similar to that in temporomandibular dysfunction, the two conditions compare well. The difference between Eagle's syndrome and TMD, however, is that Eagle's syndrome has *a* biomedically explainable cause for the development of the disease - namely overlong bony processes in the neck. However, due to the rarity and low awareness of Eagle syndrome, sufferers face similar challenges to TMD patients in finding a diagnosis and appropriate treatments. Therefore, in the empirical part, the study of both groups follows with the aim of gaining knowledge about Eagle syndrome and its potential stigma as well as its impact on the social life of those affected.

5 Empirical study

The previous chapters have presented the current state of research in the field of the two chronic diseases of the head/neck region. Points of view of stigmatisation were dealt with on the basis of specialist literature and their influence on the quality of life and social relationships of TMD patients was highlighted. The focus was placed on temporomandibular dysfunction, especially as this is far better researched than Eagle's syndrome, of which only a few studies exist. The few articles and case studies on Eagle's syndrome have only addressed the clinical course and possible surgical interventions. This study focuses on the socio-psychological aspects of this rare disorder and is the first of its kind to address non-medical factors.

After the detailed theoretical part, the empirical investigation of the diploma thesis will follow. The aim of this study is to gain new insights into Eagle syndrome and to expand the knowledge in this field. The evaluation is based on quantitative questionnaires, which were conducted online and were therefore accessible to a wide range of patients from all over the world.

5.1 Problem and research question

The subject of the thesis being written is the potential perception of stigma by Eagle syndrome patients with chronic pain in the neck, head and face area and its possible influence on social relationships. The planned study will focus on two groups of patients: those with the under-researched Eagle syndrome (also known as stylohyoid syndrome) and those with temporomandibular disorders (TMD). The aim is to find out whether there are differences or similarities in the perception of a stigma between the two groups of patients.

Indeed, studies by Lennon, Link, Marbach and Dohrenwend (1989 and 1990) have shown that a large proportion of those TMD patients who seek clinical treatment for their temporomandibular pain and orofacial dysfunction often perceive stigmatisation by medical professionals and others.

As there is no biomedically explainable cause for the development of this type of facial pain, it is often considered to be psychogenic (Zakrzewska 2002). However, sufferers perceive the pain as a physical symptom and therefore often search for satisfactory diagnoses that explain their pain (Kotarba 1983) as well as (conventional) treatment options. Both attempts are largely unsuccessful and can therefore reinforce pejorative labelling. According to Lennon et al. (1989), various factors such as the frequency of consultations with doctors or the fact that many of these patients are told by their doctors that their pain is imaginary often create a perception of stigma among those affected. According to the study, the majority of this group feels alienated and misunderstood because of their pain experience. Depending on the social context, TMD sufferers develop two different management strategies to deal with this: disclosing their treatment attempts, or keeping them secret from others. The study also points to a correlation between the degree of alienation (sometimes pain) and perceived dissatisfaction in intimate relationships.

Based on the existing theory of Lennon et al. (1989), it is assumed in the study of this thesis that the subjects of the current TMD group also suffer from stigmatisation. The focus of the study is therefore on the second group of Eagle syndrome patients, for whom no data exist at this time.

However, unlike temporomandibular dysfunction, Eagle's syndrome has an organic cause, namely one or two elongated bones in the neck (Blackett et al. 2012). Nevertheless, Eagle syndrome patients face comparable challenges to TMD patients, especially as they have chronic pain in a similar region: Pharyngeal pain, sore throat, swallowing and voice disorders, foreign body sensation ect. Many of them also have a high frequency of visits to the doctor. This can be attributed to the rarity of the disease. It is described in the literature with a prevalence of 0.16% (Ilguy et al. 2005). In addition, there are the associated difficulties for medical professionals to make the correct diagnosis as well as to treat the disease.

The present part will now investigate whether Eagle syndrome patients are also vulnerable to stigmatisation and the resulting consequences for social relationships for the reasons mentioned above. The following research question and sub-questions arise:

Do ES patients feel similarly stigmatised as TMD patients because of their disease and do they experience adverse consequences in their social life as a result?

- Are there differences in perceived stigma between the two populations?
- Are there parallels in social satisfaction/interaction and loneliness between the two groups of patients?
- Does the number of doctors affect the perception of a stigma from the perspective of ES & TMD subjects?
- What are the links between perceived stigma and patients' social lives?

5.2 Objectives and hypotheses:

In order to be able to shed light on the extent to which Eagle syndrome patients feel stigmatised in comparison to TMD patients and whether their social life is influenced by this, the following hypotheses are tested in this thesis:

Null hypothesis (H_0):

The disease (in contrast to TMD patients) does not influence the perception of possible stigmatisation of Eagle syndrome patients and therefore does not cause negative consequences for their social relationships.

Alternative hypothesis (H_1):

The disease (similar to TMD patients) creates a perception of stigma in Eagle syndrome patients, which in turn has a negative impact on their social relationships.

Target:

On the one hand, the study intends to clarify whether ES sufferers, similar to the group of TMD patients seeking medical care, are exposed to the possible problems of stigmatisation and, if so, whether this has a negative influence on social relationships. On the other hand, the study aims to provide a deeper understanding of Eagle syndrome and, in the best case scenario, to counteract a potential pejorative labelling of this group of patients.

5.3 Methodology

In this section, the individual planning steps of the explanatory study are formulated and the operationalisation is described in detail step by step. The evaluated results are then documented and interpreted. The discussion concludes by addressing the problems formulated in advance.

5.3.1 Theoretical approach:

First, the questionnaire was created in an online programme. The survey consisted of several parts, which are described in more detail in the chapter "Study design". An information sheet was prepared in advance for the participating patients, taking into account the ethical framework conditions. This described in detail what the participants could expect in the study and how it would proceed. Participation was voluntary and could be terminated at any time in between. It was pointed out that the data would be used exclusively for scientific purposes, would be treated confidentially and that the anonymity of the test persons would be guaranteed in any case. The test persons were also informed about the background of the study and that it was being conducted at the University of Vienna. They were given a contact address to which they could turn for further questions. They were asked to answer the questionnaire carefully and to the best of their knowledge. Lastly, it was emphasised that their participation can provide important information for the area being researched.

The subjects were recruited via online social media websites (support group of chronically ill people). One questionnaire was made available to the Eagle syndrome patients and one to the TMD subjects. The questionnaires were identical. The call for participation and the questionnaire itself were formulated in English.

After a period of about half a year, enough data was available so that access to the two questionnaires could be closed. The data was analysed and the hypotheses were tested. The results are documented in the thesis, compared and discussed in relation to the research question. The limitations of the study are pointed out, as well as its significance for those affected, their environment and in the clinical field. At the end of the thesis, it should be clarified whether the previously formulated research hypothesis can be provisionally accepted or must be rejected.

In a first step, the characteristics of both patient groups are presented in descriptive statistics. In a second step, the two samples are examined with regard to their differences or similarities, as well as analysed for correlations of individual characteristics of test persons within the same population. For comparison, the mean value is calculated by adding the points achieved for the items from the respective scales and then dividing by the number of items. Correlations of the different variables are calculated. Appropriate significance tests (independent samples t-test) are used to test whether the relevant measurement results are consistent with the null hypothesis or not. The study by Lennon et al. (1989) is also used for comparison. In a final step, the results are described and interpreted.

5.3.2 Ethical framework:

In accordance with the ethical guidelines of the American Psychological Association (APA) and the Ethics Committee of the University of Vienna, care is taken to preserve the integrity of the participants in the study. Patients are treated with respect and sincerity and no negative consequences may arise for them as a result of the interview. They must not be harmed, nor must the interview be otherwise detrimental to their dignity.

The data may only be used for (health) psychological, socio-cultural and clinical research purposes. The data was only processed with the explicit consent of the test persons. Therefore, they were also adequately informed about the purpose of the study at the beginning. The description of the study procedure was formulated in a way that could be understood by all. Since the survey took place online, particular importance was attached to confidentiality and seriousness. In order to enable the participants to ask questions, a contact address of the person conducting the study was given. The researcher is aware of her responsibility and will act exclusively for the greatest possible benefit of all participants.

5.4 Research design:

A cross-sectional study using a written questionnaire was chosen as the data collection strategy. This is a quantitative, hypothesis-testing, deductive approach. The independent variable in this study is the disease (either TMD or ES), while the potential experience of stigma and its influence on social relationships is the dependent variable.

At the beginning of the questionnaire, data was collected regarding socio-demographic characteristics, which provided information on the following: Age, origin, education level, partner status/family status, work status, onset of complaints/duration of the disease, time of diagnosis, styloidectomy (=removal of the bone process), i.e. operations in the affected pain area.

Following the study by Lennon et al. (1989), the following was determined using a questionnaire, the majority of the parts of which were based on their data collection except for the last two sections:

- the extent of stigmatisation (always for both patient groups)
- the patient labelling
- the severity of the pain
- Satisfaction with social relationships/social interaction as well as the degree of social/emotional loneliness.

Measuring instruments:

- ***Stigma - Scales***
  The potential perception of a stigma was measured using 4 different scales (developed by Link, Marbach and Lennon 1985). The scales are dedicated to the main topics: Attribution of personality problems (5 items), alienation (6 items), secrecy of disease treatment (6 items), disclosure of disease treatment (5 items).
  The coding of these scales ranges between 6 points (fully agree) and 1 point (strongly disagree).

Item examples of the stigma scales (translated from English):

(Note: The general term "this type of pain" is deliberately used to make the questionnaire consistent for both ES and TMD patient groups. For Eagle syndrome patients, it is synonymous with the neck pain and the other symptoms. For patients with temporomandibular dysfunction, it is synonymous with facial and jaw pain).

Many people assume that a person suffering from this type of pain also has a deep-seated psychological problem.
One problem with this kind of pain is that people don't think it really hurts.
I sometimes wish people could see my pain.
Most people have no idea what it is like to have this kind of pain.
If an employer knows that a person has a history of treatment for this type of pain, they are likely to skip the application in favour of someone else.
I have learned that it is better to keep to myself that I am in pain.
Once I started treatment for my type of pain, I was inclined to educate others about the experience.

- ***Labeling - Measurement***
  On the basis of 2 questions, the number of different doctors involved was ascertained on the one hand, and on the other hand it was found out whether the participant had already been told that she was only imagining the pain.

How many different healthcare professionals have you consulted since the onset of your condition? (number)
Have you been told by a doctor that you are just imagining the pain? (Yes/No)

- ***Measurement of the degree of pain***
  With the help of 2 different measurement techniques, both the pain intensity in numerical terms (0-10) and the experienced pain-related impairment in daily life are to be shown. The evaluation of pain chronification is done by means of a point score, which is divided into different degrees. Unlike Lennon's study (1989), two contemporary measurement methods are used for this:
    - Graded Chronic Pain Scale (Von Korff, Ormel et al. 1992) - 7 items
    - Visual Analogue Rating (Huskisson 1974)

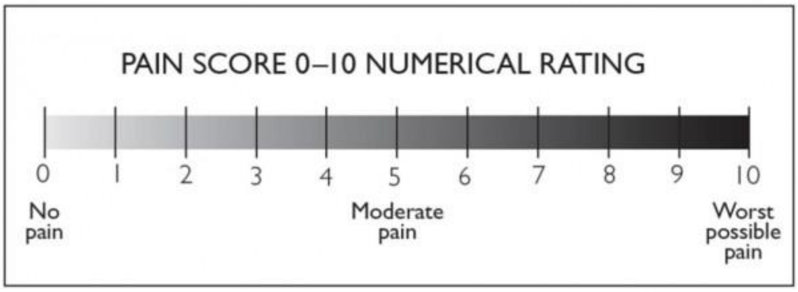


Figure 14: Visual Analogue Pain Scale (VAS) [10]

- ***Measuring satisfaction, interaction and loneliness in social life***

  This part of the study is dedicated to the social life of the patients. For this, we deviate from Lennon's study (1989) by using two other, more up-to-date scales as measurement techniques.

  - The Duke Social Support Index (according to Wardian et. al. 2013) with 10 items
  - The De Jong Gierveld Loneliness Scale - short version (De Jong Gierveld and Van Tilburg 2006) with 6 items

  Both scales are divided into two sections. The Support Index asks about social satisfaction and social interaction. The Loneliness Scale measures both social and emotional loneliness.

  Item examples of the scales just mentioned (translated from English):

Do you feel that you understand your family and friends (i.e. people who are important to you)? (Answer options: almost never, sometimes, most of the time)
Do you find you have a definite role (clear place) within your family and circle of friends? (Answer options: almost never, sometimes, most of the time)
I feel a general emptiness. (Answer options: yes, more or less, no)
I miss people around me. (Answer options: yes, more or less, no)
I often feel abandoned. (Answer options: yes, more or less, no)

---

[10] Source Figure 14: https://www.physio-pedia.com/Numeric_Pain_Rating_Scale (12.5.2019).

Sample:

The two samples each represent the patient group of one disease. The experimental group is people with Eagle syndrome (ES), while the control group consists of people with temporomandibular dysfunction (TMD). The control group therefore consists of TMD sufferers, as earlier studies by Lennon et al. (1989) already showed that those TMD patients who make more treatment attempts due to their facial pain often experience changes in the quality of their social relationships, in addition to an increased susceptibility to stigma. So ideally, both groups of patients should be actively seeking appropriate treatment options.

In order to recruit as many participants as possible, the patients of both groups (ES and TMD) were recruited online via social networks. In this case, the digital age was a great advantage of the study, especially as it made it possible to overcome the local limitations. The special feature of the study is that it was internationally accessible and patients from all over the world could participate. Due to the increased involvement of women, the study - just like that of Lennon et al. (1989) - is limited exclusively to female participants.

Participation criteria:

- Duration of pain of at least 1/2 year (from the 6th month=chronification)
- In medical treatment - being/was/seeking medical care.
- Female
- Diagnosis of ES or TMD

In the following chapter, the results of the evaluation are listed and interpreted and discussed in a next step.

6 Results & Interpretation

The statistics are documented in the following chapter.[11] It should be remembered that for reasons of space (in the tables) the abbreviations ES for Eagle's syndrome and TMD for temporomandibular dysfunction are used respectively.

6.1 Descriptive statistics

A total of 63 women took part in the study. Of these, 42 had Eagle syndrome and formed the experimental group. For the control group, exactly half, i.e. 21 TMD patients could be encouraged to participate in the study. The number of ES study participants is relatively large compared to the rarity of the disease and therefore gratifying. (1 participant had to be excluded from the evaluation because she did not fulfil the participation criteria. This has already been deducted from the above figures).

Age

Most ES participants (40.5%) were between 41-50 years old, with the second most (26.2%) being even older, between 51-60 years old. Almost 12% were over 60. 14.3% fell into the 31-40 category. Only 7.1% of the ES patients in the study reported being under 30.

In the TMD control group, the distribution was contrary. Almost half of the participants (47.6%) belonged to the youngest age category (under 30). The remaining participants were divided into 2 other categories, 31-40 and 41-50.

Origin

The ES patients in the study were distributed across 4 different continents. The majority of the ES participants live in North America. The others reported living in Europe and Australia or New Zealand. 1 respondent lives in Africa.

---

[11] In the descriptions, the values are rounded to 1 decimal place for better clarity; in the tables, the exact values are given to 2 decimal places.

The counterpart to America for Eagle syndrome patients was Europe for the TMD group. The majority of the group reported living on the European continent. A much smaller proportion live in North America and 2 people live in Asia.

Table 1: Origin of the test persons

	ES		**TMD**	
Continent	**N**	**%**	**N**	**%**
North America	26	61,90%	5	23,81%
Europe	9	21,43%	14	66,67%
Australia	6	14,29%		
Africa	1	2,38%		
Asia			2	9,52%
Total	**42**	**100,00%**	**21**	**100,00%**

In terms of nationality, the participants were divided into very different categories. The majority of the ES participants were originally from the USA, while others were Canadian. They also included 1 Mexican and 1 Native American. In Europe, the Eagle syndrome sample was composed of British, Irish, German and French women. Subjects from the Netherlands, Italy, Slovenia, Slovakia and 1 participant with an original Indian nationality also took part in the study.

The nationalities of the TMD subjects ranged from the Philippines, Lebanon, Palestine, Poland, Finland, Austria, England, Germany, to America, Canada, and many more.

Educational level

What was striking in both groups was the high percentage of women with a university or college degree (45.2% in ES & 61.9% in TMD).

Relationship status & marital status

While almost three quarters of the ES subjects (73.8%) were married, only about one third (33.3%) of the TMD subjects were married. Exactly one third of the TMD patients were single. The contrast between the two samples is most likely due to the different age distribution of the patients (the TMD control group was mostly composed of a much younger age group >30).

The situation is similar when it comes to having children of their own. 61.9% of ES women already have children, while almost as many (66.7%) of TMD women do *not.*

Working status

More than half (57.1%) of the ES patients were *not in* paid employment at the time of the study. However, all participants (100%) stated that they had been in paid employment before the disease. This suggests that the pain has a significant impact on their ability to work. More than every second person with the disease is prevented from working because of the complaints.

The result of the TMD patients is different. Here, exactly two thirds (66.7%) were *in* paid employment at the time of the survey and only one third were not. Thus, it can be concluded that facial pain has a less drastic effect on the ability to work than the symptoms of Eagle's syndrome.

Degree of severity of the pain

- Duration of the pain from the onset of the disease

26.2% of the Eagle syndrome subjects had been suffering from the pain for more than 15 years. Exactly the same number (26.2%) reported having pain between 5 and 10 years. 19% had the condition for more than 10 years and 21.4% between 1 and 5 years. Only 7% of the ES participants had the condition for about half a year.

Among the TMD patients in the study, the majority (57.1%) had pain between 1 and 5 years. The second largest group, 23.8%, had pain between 5 and 10 years. Compared to the ES group, much fewer, only 9.5%, had been in pain for more than 15 years. (This may also be due to the young age of the TMD subjects in the study).

Table 2: Duration of pain since onset of illness

	ES		**TMD**	
Pain duration	**N**	**%**	**N**	**%**
> half year	3	7,14%	1	4,76%
1 to 5 years	9	21,43%	12	57,14%
5 to 10 years	11	26,19%	5	23,81%
> 10 years	8	19,05%	1	4,76%
> 15 years	11	26,19%	2	9,52%
Total	**42**	**100,00%**	**21**	**100,00%**

- Time to diagnosis

Table 3 below shows how long it took on average for the patients in the study to receive the correct diagnosis. The most common response category for both populations was 1-5 years. 26.2% of the ES subjects had to wait more than 10 years for their correct diagnosis. For TMD, on the other hand, the maximum duration was 5-10 years.

Table 3: Time to diagnosis

	ES		**TMD**	
Time until diagnosis	**N**	**%**	**N**	**%**
< 1 month	3	7,14%	3	14,29%
< half year	3	7,14%	7	33,33%
1 to 5 years	15	35,71%	9	42,86%
5 to 10 years	10	23,81%	2	9,52%
> 10 years	11	26,19%		0,00%
Total	**42**	**100,00%**	**21**	**100,00%**

Table 4 shows the average time to diagnosis that women had to wait - again divided into the two diseases ES and TMD, this time sorted by continent. Depending on the location, the time to diagnosis varied. In order to be able to make a general statement about how long sufferers have to wait on average for their diagnosis depending on the continent, however, the sample would have to be much larger. Thus, the table cannot be generalised, but it provides detailed information about the test persons of the present diploma thesis.

In Europe, for example, the majority of resident ES subjects (23.8%) and almost half (9.5%) of all European-born TMD patients had to wait between 5 and 10 years for their diagnosis.

The highest response category and thus the longest time span (more than 10 years) was the second most common response for Eagle syndrome patients in Australia, Europe and North America, and even the first most common in Australia together with another category - in contrast to TMD, where no person had to wait longer than 10 years for their diagnosis.

Table 4: Time to diagnosis by continent

	ES		TMD	
Time until diagnosis	**N**	**%**	**N**	**%**
North America	**26**	**61,90%**	**5**	**23,81%**
< 1 month	3	7,14%		
< half year	1	2,38%	3	14,29%
1 to 5 years	10	23,81%	2	9,52%
5 to 10 years	5	11,90%		
> 10 years	7	16,67%		
Europe	**9**	**21,43%**	**14**	**66,67%**
< 1 month			2	9,52%
< half year	1	2,38%	3	14,29%
1 to 5 years	2	4,76%	7	33,33%
5 to 10 years	4	9,52%	2	9,52%
> 10 years	2	4,76%		
Australia	**6**	**14,29%**		
< half year	1	2,38%		
1 to 5 years	2	4,76%		
5 to 10 years	1	2,38%		
> 10 years	2	4,76%		
Africa	**1**	**2,38%**		
1 to 5 years	1	2,38%		
Asia			**2**	**9,52%**
< 1 month			1	4,76%
< half year			1	4,76%
Total	**42**	**100,00%**	**21**	**100,00%**

- <u>Attempt at healing by means of surgical intervention</u>

Almost 43% of ES patients reported having already had neck surgery. The majority of them (66.7%) have undergone only one operation. 16.7% of the participants had attempted the operation 2-3 times and another 16.7% had even undergone more than 3 operations. On the question of whether the surgical shortening of the bones resolved the symptoms, 61.1% said that only some symptoms were relieved, but they still had pain. The other participants gave different reasons: that the pain stayed the same, that the pain came back later, that it was even worse after the surgery, and so on. The statements were all negative, which was not surprising, especially since the prerequisite for participation in the study was an existing pain problem.

This shows that although surgery for Eagle's syndrome is not always successful, it is still indicated and performed in many cases of severe pain symptoms or long/peak/disruptive bone lengthening.

In comparison, only 19% of the TMD participants in this study underwent one or two operations. But even these participants were still in pain at the time of the study.

- Current pain intensity

The average pain intensity of the participants in the last 24 h before the study was carried out was approximately *5.7 in* both populations - i.e. approximately in the middle of the analogue pain scale used. The scale ranged from 0-10 (0 no pain - 10 worst pain there is). The evaluation showed that there was no real tendency and that the pain intensity of the past day was very different for all participants. Only among the TMD women did a larger proportion have a pain intensity of about *7* points.

- Degree of chronification

The degrees of chronification are divided into 4 different categories, where 4 is the highest severity and 1 is the lowest. The degrees indicate how much the pain has already become chronic and how it affects the patients' everyday life. Thus, both the intensity of the pain and the pain-related impact on the lives of those affected were measured.

Table 5 shows that most of the subjects in both ES and TMD had very high degrees of pain chronicity, mainly grade 3 and 4. The highest proportion of grade 4 severity, 40.5%, was in Eagle syndrome patients. 35.7% were classified as grade 3. TMD patients reached only 19.1% in the highest category, but more than half (57.1%) fell into severity grade 3.

Table 5: Classification of the degree of pain chronification

Degree of pain chronification	**ES**		**TMD**	
	N	**%**	**N**	**%**
Grade 1	6	14,29%	2	9,52%
Grade 2	4	9,52%	3	14,29%
Grade 3	15	35,71%	12	57,14%
Grade 4	17	40,48%	4	19,05%
Total	**42**	**100,00%**	**21**	**100,00%**

Stigma and its management

The agreement of the scale "attribution of personality problems" tended to be several percent higher in the control group of TMD patients than in the ES patients, ranging from 31-50%. The agreement of the ES patients varied from 31-45%.

Also in the alienation scale, the TMD patients have higher percentages of agreement on some items than the ES test group. For example, for the item "I sometimes wish people could see my pain", 95.5% of TMD subjects agreed and "only" 71.4% of ES patients agreed, which is still a high rate of agreement. Eagle syndrome patients had a higher rate of agreement (85.7%) with the item "I often feel alone with my pain".

On the disease treatment confidentiality scale, both samples scored highest on the item: "If an employer knows that a person has a history of treatment for this type of pain, they are likely to skip the job application in favour of someone else. "Similarly, half of the ES patients and 63.6% of the TMD patients said they had learned it was better to keep to themselves that they had pain.

The scale for the disclosure of the treatment of the illness achieved between 40 and 50% agreement. Only one item was significantly lower in both groups at less than 10% - this was about meeting a new friend whom one would first tell about one's pain. The level of agreement here was very low and in this respect points more to the strategy of secrecy.

The mean value of the individual items was 3.5. The range was from 1-6. If the value is greater than 3.5, this means that the patients were more in favour of the items. Table 8 shows that no value falls below the mean. The patients in both groups therefore tended to agree with the items. They did not differ in this respect. Thus, the first part of the research question can already be answered with yes:

ES patients feel similarly stigmatised as TMD patients.

Table 6: Agreement of the stigma scales

	ES			TMD			Difference		
	Consent %	Item Mean value	S.D.	Consent %	Item Mean value	S.D.	State %	Item M	S.D.
Attribution of personality problems - scale									
22. when people notice that you have been treated for your kind of pain, they start looking for weaknesses in your personality.	35,71%	3,6	1,8	31,82%	3,6	1,8	3,90%	0,0	0,0
23 Many people assume that having this kind of pain is a sign of personal weakness.	33,33%	3,7	1,7	40,91%	3,7	1,8	-7,58%	0,0	-0,1
24. most people believe that a person with your kind of pain is as emotionally stable as the average person. *R	30,95%	3,6	1,6	45,45%	3,4	1,9	-14,50%	0,2	-0,3
25. many people assume that a person suffering from this type of pain also has a deep-seated psychological problem.	45,24%	3,8	2,0	50,00%	3,8	1,7	-4,76%	0,0	0,3
26. people tend to associate the occurrence of your type of pain with psychiatric difficulties.	45,24%	3,8	1,9	50,00%	3,8	1,8	-4,76%	0,0	0,1
Alienation scale									
27. there is a part of me that only other people who have experienced my kind of pain can understand.	88,10%	5,5	1,2	90,91%	5,5	0,9	-2,81%	0,0	0,2
28. one problem with this kind of pain is that people don't think it really hurts.	66,67%	4,8	1,7	81,82%	4,8	1,1	-15,15%	0,0	0,6
29. sometimes I wish people could see my pain.	71,43%	5,0	1,7	95,45%	5,0	0,7	-24,03%	0,0	0,9
30. my kind of pain made me feel very different from other people.	80,95%	5,3	1,1	77,27%	5,3	1,3	3,68%	0,0	-0,2
31 Most people have no idea what it is like to have this pain.	78,57%	5,2	1,3	90,91%	5,2	0,8	-12,34%	0,0	0,5
I often feel completely alone with my pain.	85,71%	5,4	1,0	77,27%	5,4	1,1	8,44%	0,0	-0,1
Secrecy - Scale									
I have told people close to me to keep it a secret that I am being treated for my type of pain.	14,29%	2,5	1,8	18,18%	2,5	1,7	-3,90%	0,0	0,1
34. if I had a close acquaintance who was treated for this kind of pain, I would advise him/her to	14,29%	2,5	1,7	22,73%	2,5	1,8	-8,44%	0,0	-0,1

tell only his/her closest confidants.									
If an employer knows that a person has a history of treatment for this type of pain, they are likely to skip the application in favour of another.	64,29%	4,6	1,7	72,73%	4,6	1,8	-8,44%	0,0	-0,1
36. if I thought an employer could discriminate against a person because of their treatment history of this type of pain, I would not apply for the job.	59,52%	4,6	1,7	40,91%	4,6	1,9	18,61%	0,0	-0,2
37. I hardly feel the need to keep secret that I have been treated for my kind of pain. *R	33,33%	3,5	1,9	22,73%	3,5	1,7	10,61%	0,0	0,2
38. I have learned that it is better to keep to myself that I am in pain.	50,00%	4,1	1,6	63,64%	4,1	1,3	-13,64%	0,0	0,3
Disclosure - Scale									
39. I have found it a good idea to help close people understand what treatments for my type of pain look like.	52,38%	4,4	1,7	40,91%	4,4	1,5	11,47%	0,0	0,2
40. when I talk to close people about my pain experience, I make a special effort to tell them about the experiences that might have triggered the pain.	45,24%	4,0	1,8	54,55%	4,0	1,3	-9,31%	0,0	0,4
41. after I started treatment for my type of pain, I was inclined to educate others about the experience.	52,38%	4,5	1,5	54,55%	4,5	1,4	-2,16%	0,0	0,1
42. I feel obliged to help educate the public about issues involving this type of pain.	40,48%	3,9	1,5	40,91%	3,9	1,6	-0,43%	0,0	-0,1
43. if I met a new friend, one of the first things I would do would be to tell him/her about my kind of pain.	7,14%	2,2	1,4	4,55%	2,2	1,2	2,60%	0,0	0,2

*R => Returned calculated

Labelling & number of doctors

The Eagle syndrome patients in the study visited about 14 different doctors/person, on average about 4 more than TMD patients, whose mean value, rounded up, is almost 10. However, the standard deviation of the results is relatively high for both groups. This is *15 for* ES patients and *9.1 for TMD* patients.

Furthermore, the t-test states that there is no significant difference in the number of doctors between the two experimental groups *(t(df=61)= 1.34; p= .19)*. Although the mean is higher for the Eagle syndrome patients in this study, the result is not significantly different. The sample size plays a role here, as the TMD group was only half the size of the ES group. It should therefore not be concluded from the results that ES patients generally see more doctors than TMD patients. However, due to the high values, it can be stated that both groups had a high number of medical staff involved. Compared to the study by Lennon et al. (1989), where the average was 6.5 doctors, the subjects of the present thesis had a much larger number.

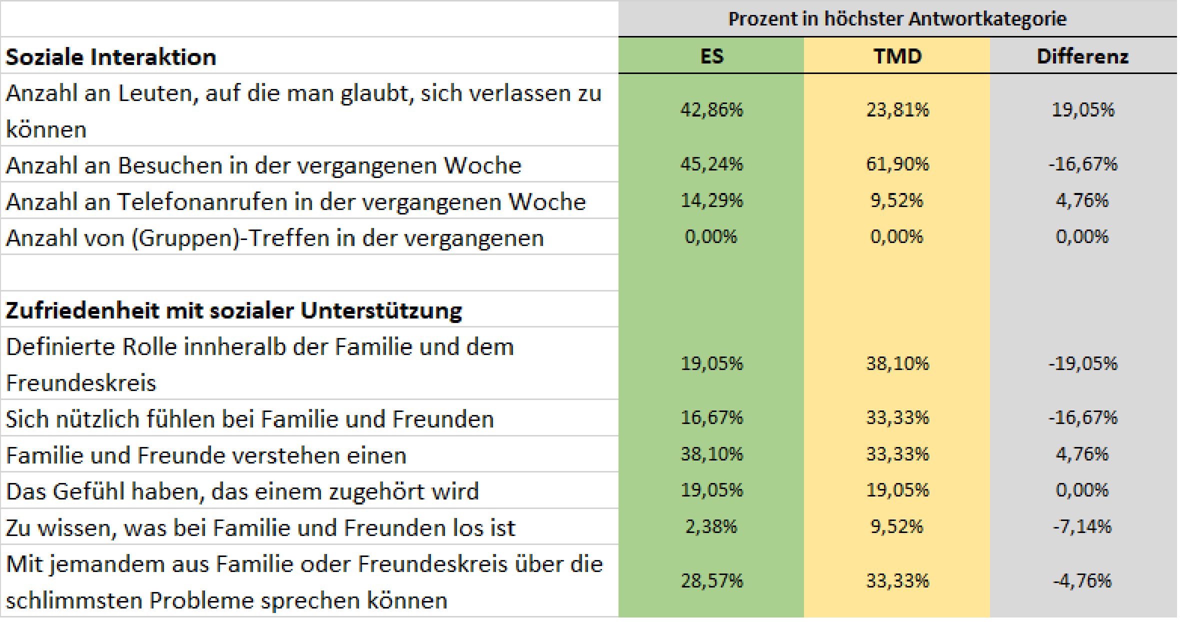
The percentage of women who were told by a doctor that their pain was just imaginary is particularly striking. It is exactly the same in both groups and is more than half (52.4%). It is also interesting to note that the researchers Lennon et al. found the exact same percentage (52%) in their study (1989). Consequently, it can be claimed that on average every 2nd ES & TMD patient is told by her healthcare professional that her complaints are imaginary. This fact is significant in that the study by Lennon et al. was conducted exactly 30 years ago (1989) and this approach has not changed to date.

Satisfaction and interaction in social life

Table 7 shows the agreement in percent of the highest possible answer category (always the best form of social interaction/satisfaction in each case). The two groups consistently achieved relatively low levels of absolute agreement and thus have relatively low levels of social interaction and social satisfaction. It can be seen that for none of the items did at least half of the Eagle syndrome patients agree with the highest category. The only highest score achieved is 45.2% for ES sufferers. The number of telephone calls made by ES sufferers, for example, marks a low level of social interaction with 14.3% in the highest category. TMD sufferers are even lower with 9.5% agreement. None of the participants (0%) regularly attended group meetings.

Satisfaction with social support was also consistently low, with ES patients scoring lower than TMD patients in most responses. Only 16.7% of ES patients feel useful to family and friends, in contrast to TMD where the percentage is 33.3, which is still low. Only 2.4% of ES patients reported knowing what was going on with their friends and family most of the time. Only 19% of all participants felt that they were listened to.

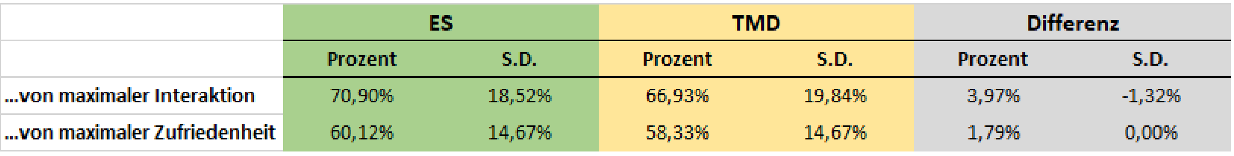
Table 7: Social life of the test persons



	Prozent in höchster Antwortkategorie		
Soziale Interaktion	**ES**	**TMD**	**Differenz**
Anzahl an Leuten, auf die man glaubt, sich verlassen zu können	42,86%	23,81%	19,05%
Anzahl an Besuchen in der vergangenen Woche	45,24%	61,90%	-16,67%
Anzahl an Telefonanrufen in der vergangenen Woche	14,29%	9,52%	4,76%
Anzahl von (Gruppen)-Treffen in der vergangenen	0,00%	0,00%	0,00%
Zufriedenheit mit sozialer Unterstützung			
Definierte Rolle innheralb der Familie und dem Freundeskreis	19,05%	38,10%	-19,05%
Sich nützlich fühlen bei Familie und Freunden	16,67%	33,33%	-16,67%
Familie und Freunde verstehen einen	38,10%	33,33%	4,76%
Das Gefühl haben, das einem zugehört wird	19,05%	19,05%	0,00%
Zu wissen, was bei Familie und Freunden los ist	2,38%	9,52%	-7,14%
Mit jemandem aus Familie oder Freundeskreis über die schlimmsten Probleme sprechen können	28,57%	33,33%	-4,76%

The next table 8 illustrates the mean value of the achieved percentages of all test persons of the two subscales, measured against the maximum interaction/satisfaction to be achieved. This was better than the agreement in percent of the highest category from the table above. Table 12 shows that TMD sufferers with almost 67% of maximum interaction and 58.3% of maximum satisfaction still scored minimally worse than ES sufferers. However, the standard deviation is relatively large for both groups (around 14-19%). In addition, the satisfaction with social support is lower than the social interaction rate for both groups. This means that contact with other people is greater than the feeling of being in good hands.

Table 8: Maximum social interaction/satisfaction



	ES		TMD		Differenz	
	Prozent	S.D.	Prozent	S.D.	Prozent	S.D.
...von maximaler Interaktion	70,90%	18,52%	66,93%	19,84%	3,97%	-1,32%
...von maximaler Zufriedenheit	60,12%	14,67%	58,33%	14,67%	1,79%	0,00%

LonelinessTable 9 illustrates the pronounced loneliness of the two patient groups broken down into age categories. Social and emotional loneliness were added up to a total score. The classification of the degrees of loneliness is divided into 3 different levels: not lonely, moderately lonely and very lonely.

The table and the graph show that both groups of patients of all ages (with the exception of the ES subjects between 31 and 40) had the highest percentages in the category "very lonely". On average, the TMD control group was several percent lonelier than the ES group.

Table 9: Loneliness of the test persons according to age

	not lonely	moderately lonely	Very lonely
ES	**11,90%**	**28,57%**	**59,52%**
< 30	0,00%	33,33%	66,67%
31-40	33,33%	50,00%	16,67%
41-50	5,88%	17,65%	76,47%
51-60	9,09%	36,36%	54,55%
> 60	20,00%	20,00%	60,00%
TMD	**4,76%**	**28,57%**	**66,67%**
< 30	0,00%	30,00%	70,00%
31-40	16,67%	16,67%	66,67%
41-50	0,00%	40,00%	60,00%
Total	**9,52%**	**28,57%**	**61,90%**

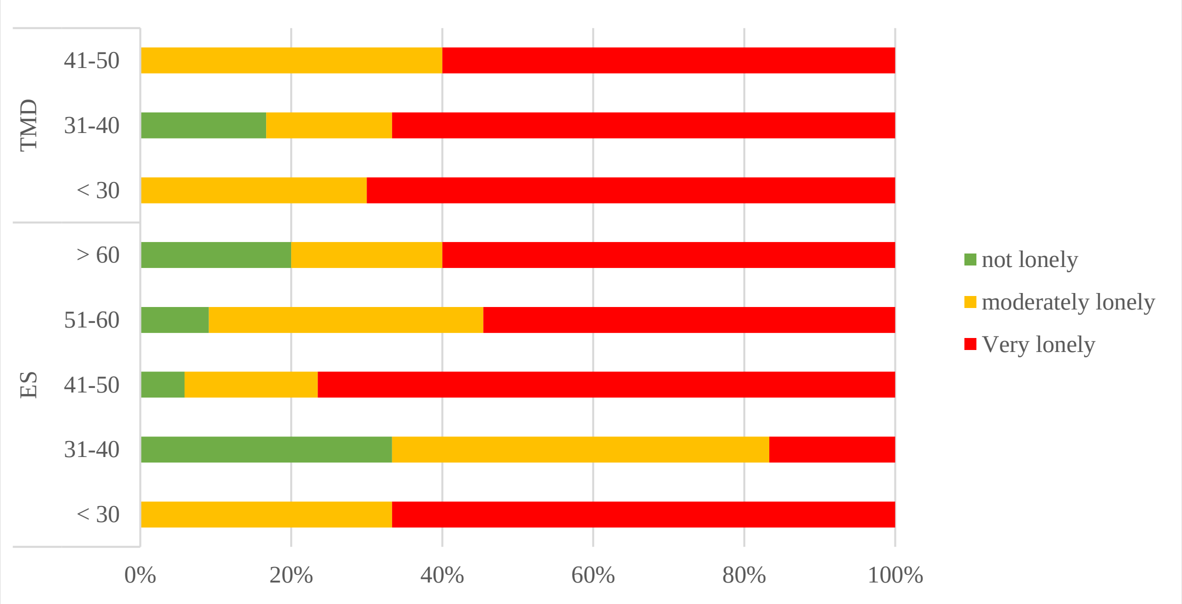


Figure 15: Loneliness of the test persons according to age

The next table and graph show the loneliness scores of the two populations, but sorted by the degree of pain chronification. Here it can be seen that people in both groups with the highest pain chronification grade 4 are the loneliest. TMD patients in this category were unanimous (100%) in stating that they were very lonely.

Table 10: Loneliness according to pain chronification

	not lonely	**moderately lonely**	**Very lonely**
ES	**11,90%**	**28,57%**	**59,52%**
Grade 1	16,67%	33,33%	50,00%
Grade 2	25,00%	50,00%	25,00%
Grade 3	13,33%	33,33%	53,33%
Grade 4	5,88%	17,65%	76,47%
TMD	**4,76%**	**28,57%**	**66,67%**
Grade 1	0,00%	50,00%	50,00%
Grade 2	0,00%	33,33%	66,67%
Grade 3	8,33%	33,33%	58,33%
Grade 4	0,00%	0,00%	100,00%
Total	**9,52%**	**28,57%**	**61,90%**

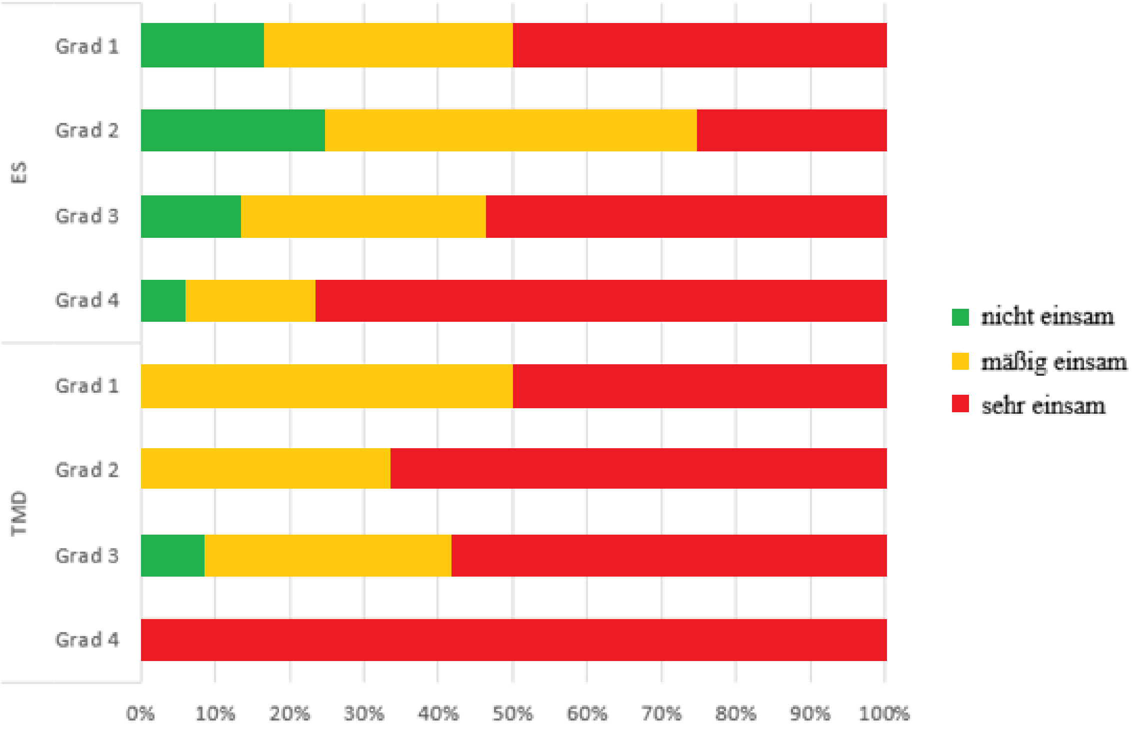


Figure 16: Loneliness after pain chronification

6.2 Inferential statistics

6.2.1 Comparison of the two samples

Table 15 lists the mean scores obtained for each of the 8 scales (4 stigma scales, 2 social life scales and 2 loneliness scales) from both samples with their respective standard deviation. There are no significant differences between the two groups, which means that the stigma as well as the affected social life is recorded in both populations.

Stigmatisation - mean values (purple)

The mean value of the individual items was *3.5 in* each case and *4.5* for the 2 middle scales (alienation and secrecy), as these each contained 1 item more. The range was from 1-6 points per item and 6-30 or 6-36 per scale. The mean scores achieved were all above the item mean for both groups and thus signalled agreement with the perceived stigma.

The agreement of the perceived alienation and the secrecy of the disease treatment shows higher points for both groups, but only because the item mean for these scales was *4.5* - in this respect, the agreement is to be evaluated as about the same as for the other 2 scales (attribution of personality problems and disclosure of disease treatment), whose item mean was *3.5.*

The scores on the perception of an attribution of personality problems are almost identical and not significantly different for ES *sufferers and* TMD sufferers *(t(df=61)= -.01; p= .99).*

The difference in alienation is minimal and not significantly different *(t(df=61)= -1.00; p= .32).*

For the management strategy "secrecy of disease treatment", the values are also almost identical and not significantly different *(t(df=61)= .22; p= .83).*

For the management strategy "disclosure of disease treatment", the values are also almost the same and not significantly different *(t(df=61)= .06; p= .95).*

Social life - mean values (blue)

The range of the **social satisfaction** scale is 6-18. If the calculation system of the above scales is adopted, the item mean is 12.5. Overall, the social satisfaction of the study participants is neither particularly high nor particularly low (see Table 15).

For both groups, the social satisfaction scores are similar and not significantly different *(t(df=61)= .78; p=.44).*

The range of **social interaction** is 4-12. The item mean is thus 8.5. Neither of the two populations reached this mean value. The social interaction of those with the disease is therefore lower than average.

The social interaction scores of both groups differ only very slightly and are not significantly different *(t(df=61)= .46; p= .65).*

Loneliness - mean values (green)

The range for both scales on emotional/social loneliness is 0-3. Loneliness is thus marked from 2. Both groups are above this item midpoint and are thus to be considered lonely.

The emotional loneliness scores are almost the same for both and not significantly different *(t(df=61)= -.32; p= .75).*

The social loneliness scores are very similar and not significantly different *(t(df=61)= -1.29; p= .20).*

Table 11: Mean comparison of stigma & social life/loneliness from both samples

Group Statistics - Stigma & Social Life/Loneliness

	Data source	N	**Mean value**	Std. deviation	Standard error of the mean
Attribution of personality problems	ES	42	**3,7095**	1,41021	,21760
	TMD	21	**3,7143**	1,30011	,28371
Alienation	ES	42	**4,2937**	,92086	,14209
	TMD	21	**4,5159**	,60988	,13309
Secrecy	ES	42	**4,5595**	1,15107	,17761
	TMD	21	**4,4921**	1,20816	,26364
Disclosure	ES	42	**3,7714**	1,10923	,17116
	TMD	21	**3,7524**	1,16774	,25482
Social satisfaction	ES	42	**12,76**	3,334	,514
	TMD	21	**12,05**	3,570	,779
Social interaction	ES	42	**7,21**	1,760	,272
	TMD	21	**7,00**	1,761	,384
Emotional loneliness	ES	42	**2,24**	1,122	,173
	TMD	21	**2,33**	1,065	,232
Social loneliness	ES	42	**2,14**	1,201	,185
	TMD	21	**2,52**	,873	,190

6.2.2 Interrelationships of the variables

This chapter is dedicated to the correlations between the individual scales mentioned above (perception of stigmatisation and social life/loneliness), as well as the correlation of the individual scales with the number of doctors visited.

Illness, Stigma & Social Life/Loneliness

The aim was to find out how the perceived stigmatisation, the management strategies and the social life as well as the loneliness of the female patients are related and whether there are (very) significant correlations. (Note: in the term "social satisfaction/interaction", the minus in front of the number marks the perceived **dissatisfaction/low** interaction).

In the perception of attribution of personality problems, the study participants showed very significant correlations with alienation *(r= .50; p< .01),* as well as social satisfaction *(r= -.48; p< . 01)* and emotional loneliness *(r= .38; p< .01).*

The greater the belief in attribution of personality problems, the greater the alienation and emotional loneliness, and the lower the satisfaction with social relationships.

In the case of alienation, in addition to the above-mentioned attribution of personality problems *(r= .50; p< .01), there* were also very significant correlations with the secrecy strategy *(r= .44; p< .01),* but also with the disclosure strategy *(r= .35; p< . 01), as well as* with social satisfaction *(r= -.47; p< . 01),* and social interaction *(r= -4.60; p< . 01)* and emotional loneliness *(r= .68; p< . 01).* The correlation of alienation and social loneliness is significant (*r= .31; p< . 05).*

The greater the alienation, the greater not only the belief that personality problems are attributed, but also the greater the use of secrecy or disclosure strategies, the lower the satisfaction with social life and social interaction, and the higher the emotional and social loneliness.

The secrecy management strategy, in addition to being very significantly correlated with alienation *(r= .44; p< .01), was* also very significantly associated with social satisfaction *(r= -.36; p< .01)* and emotional loneliness *(r= .35; p< .01).*

The more the secrecy strategy is used, the higher the alienation, emotional loneliness and the lower the social satisfaction.

The disclosure strategy also shows a very significant correlation with alienation $(r= .35; p< .01)$ *and* a significant correlation with perceived emotional loneliness $(r= .31; p< .05)$.

The more the disclosure strategy is used, the higher the alienation, as well as emotional loneliness.

Social satisfaction correlates with all the variables mentioned except disclosure strategy.

In addition to the above-mentioned correlations, social interaction also correlates very significantly with social satisfaction $(r= .55; p< .01)$.

The higher the social interaction, the higher the social satisfaction.

Emotional loneliness, as already included above, correlates very significantly with all the variables mentioned and significantly with disclosure management strategy.

Social loneliness correlates very significantly with social satisfaction $(r= -67; p< .01)$, social interaction $(r= -.41; p< .01)$ and emotional loneliness $(r= .50; p< .01)$, *in* addition to alienation $(r= .31; p< . 05)$,

The higher the social loneliness, the stronger is not only alienation but also emotional loneliness and the lower is social interaction and social satisfaction.

Correlations of both groups of patients

Table 12: Correlations of both samples

		Attribution score	Estrangementscore	Secrecyscore	disclosurescore	Social Loneliness Sum	Emotional loneliness sum	Social Interaction Subscale	Social Satisfaction Subscale
Attribution score	Correlation according to Pearson	1	,496 **	,239	,108	,131	,377 **	-,185	-,478 **
	Significance (2-sided)		,000	,059	,400	,306	,002	,146	,000
	N	63	63	63	63	63	63	63	63
Estrangementscore	Correlation according to Pearson	,496 **	1	,438 **	,352 **	,313 *	,677 **	-,460 **	-,474 **
	Significance (2-sided)	,000		,000	,005	,013	,000	,000	,000
	N	63	63	63	63	63	63	63	63
Secrecyscore	Correlation according to Pearson	,239	,438 **	1	,012	,176	,349 **	-,134	-,363 **
	Significance (2-sided)	,059	,000		,927	,169	,005	,296	,003
	N	63	63	63	63	63	63	63	63
disclosurescore	Correlation according to Pearson	,108	,352 **	,012	1	,008	,313 *	-,062	-,018
	Significance (2-sided)	,400	,005	,927		,952	,013	,631	,889
	N	63	63	63	63	63	63	63	63
Social Loneliness Sum	Correlation according to Pearson	,131	,313 *	,176	,008	1	,496 **	-,411 **	-,666 **
	Significance (2-sided)	,306	,013	,169	,952		,000	,001	,000
	N	63	63	63	63	63	63	63	63
Emotional loneliness sum	Correlation according to Pearson	,377 **	,677 **	,349 **	,313 *	,496 **	1	-,483 **	-,636 **
	Significance (2-sided)	,002	,000	,005	,013	,000		,000	,000
	N	63	63	63	63	63	63	63	63
Social Interaction Subscale	Correlation according to Pearson	-,185	-,460 **	-,134	-,062	-,411 **	-,483 **	1	,551 **

	Significance (2-sided)	,146	,000	,296	,631	,001	,000		,000
	N	63	63	63	63	63	63	63	63
Social Satisfaction Subscale	Correlation according to Pearson	-,478 **	-,474 **	-,363 **	-,018	-,666 **	-,636 **	,551 **	1
	Significance (2-sided)	,000	,000	,003	,889	,000	,000	,000	
	N	63	63	63	63	63	63	63	63

**. The correlation is significant at the 0.01 level (2-sided).

*. The correlation is significant at the 0.05 level (2-sided).

Number of doctors, label & stigma

Table 13 below shows the significant correlation between the number of doctors seen by all study participants since the onset of the disease and the perception of attribution of personality problems *($r= 32; p< .05$).*

The more doctors are consulted, the stronger the attribution of personality problems is felt.

Otherwise, there were no significant correlations. However, if patients believe they have personality problems, this in turn affects the other variables, as described in the correlations above. There were correlations with high alienation and emotional loneliness, as well as low satisfaction with social life. Thus, although there is no direct correlation with the number of doctors consulted, this can have an indirect effect on the other factors.

Table 13: Number of doctors since onset of illness

		Attribution of personality problems	Alienation	Secrecy	Disclosure	Social loneliness	Emotional loneliness	Social interaction	Social satisfaction
Number of doctors consulted since onset of illness	Correlation according to Pearson	,319 *	,079	-,036	-,032	,062	,035	-,117	-,062
	Significance (2-sided)	,011	,540	,777	,806	,632	,785	,361	,631
	N	63	63	63	63	63	63	63	63

*. The correlation is significant at the 0.05 level (2-sided).

For the ES patients, there was a significant association between the number of doctors seen and attribution of personality problems $(r=.38\ p< .05)$. Otherwise, there were no significant correlations. For the exact figures, see Table 14.

Table 14: Relationship between number of doctors, label, stigma - ES group

		Attribution of personality problems	Alienation	Secrecy	Disclosure	Social loneliness	Emotional loneliness	Social interaction	Social satisfaction
Number of doctors consulted since onset of illness	Correlation according to Pearson	,384*	,225	-,013	-,054	,074	,145	-,267	-,110
	Significance (2-sided)	,012	,152	,935	,735	,641	,359	,087	,487
	N	42	42	42	42	42	42	42	42

*. The correlation is significant at the 0.05 level (2-sided).

In the TMD patients of the study, however, there was a significant correlation between the number of doctors visited and the subjects' perceived alienation $(r= .52;\ p< .05)$. Otherwise, there were no significant correlations. For the exact figures, see table 15.

Table 15: Relationship between number of doctors, label, stigma - TMD group

		Attribution of personality problems	Alienation	Secrecy	Disclosure	Social loneliness	Emotional loneliness	Social interaction	Social satisfaction
Number of doctors consulted since onset of illness	Correlation according to Pearson	,125	-,522*	-,139	,028	,174	-,320	,327	,005
	Significance (2-sided)	,589	,015	,548	,904	,450	,158	,148	,982
	N	21	21	21	21	21	21	21	21

*. The correlation is significant at the 0.05 level (2-sided).

It is interesting to note that the two samples analysed split up - depending on the doctor consultation - each perceive a different form of stigmatisation. While ES patients have the impression that psychological weaknesses such as an unstable personality and emotional imbalance are attributed to them, TMD patients tend to feel completely different from all other people, i.e. alienated. One possible explanation for the difference could be that ES patients are more certain of their physical discomfort because they can prove an organic cause on their X-ray/CT images once they have a diagnosis.

In this respect, it is understandable that TMD patients, who often only receive psychological explanations, feel misunderstood because other people do not necessarily have to believe that they are really in pain, especially since there is no obvious proof of this.

Conclusion

Overall, there were many (very) significant correlations between stigmatisation and its negative influence on social life. Thus, the second part of the research question can also be answered in the affirmative:

Due to the perception of stigma, Eagle syndrome patients experience adverse consequences in their social life.

The sub-headings of the research question are answered as follows:

- There are no significant differences in perceived stigma between the two populations (ES & TMD).
- There are clear parallels in social satisfaction/interaction and loneliness between the two groups of patients.
- The number of doctors has a significant effect on the perception of a stigma from the perspective of the ES & TMD subjects.
- There are (very) significant correlations (see above) between perceived stigma and the patients' social life.

6.3 Summary

With both diseases, there is a considerable perception of stigma from the patients' point of view. This ranges from the perception that other people would attribute personality problems, psychological weaknesses and emotional instability to feelings of alienation, separation and being "different from everyone else" to the acquisition of various management strategies to deal with the disease treatment in public. The impression of being stigmatised by other people has a negative effect on the satisfaction with social life for both groups of patients or brings about less social interaction and therefore causes high social and emotional loneliness among the patients.

7 Discussion

The chosen samples of the 5 continents represented the respective patient groups (ES & TMD) very well in that both populations showed very high degrees of pain chronification, as well as a long duration of pain and a high number of doctors consulted. Whereas in the comparative study by Lennon et. al (1989) the average number of doctors consulted by TMD patients was only 6.5, the study participants in the present thesis were significantly higher with approximately 14 (ES) and 9.6 (TMD). Just as in the study by Lennon et al., more than half of all patients in both groups in the present study were told by a health professional that their pain was just imaginary.

In addition, both groups of the present study showed a long waiting time until the correct diagnosis was made, which further favoured the prerequisite of perceived stigmatisation up to negative consequences for social life. On the one hand, these aspects support the previously described theories of the literature in the first part of the thesis, and on the other hand, they were an ideal starting point to answer the research question of this study, which was:

Do ES patients feel similarly stigmatised as TMD patients because of their disease and do they experience adverse consequences in their social life as a result?

In a first step, it was hypothesised that the TMD patients in this study (control group) - just like the TMD subjects in Lennon's study (1989) - experience stigmatisation. This could be confirmed. In addition, it was also found that - as assumed - the TMD patients in this study do not show particularly good values of social satisfaction/interaction, but that the majority of all TMD patients experience strong loneliness.

The next step was to investigate whether Eagle syndrome patients (experimental group) also suffer from such phenomena. The results showed that due to the factors mentioned (chronicity, duration of pain, waiting time until diagnosis, number of doctors, suspected conceit, etc.), Eagle syndrome patients also experience precisely these phenomena (stigmatisation and negative effects on social life). Thus, the postulated alternative hypothesis (H_1) can be confirmed:

The rare disease "Eagle syndrome" (similar to the much better known disease TMD) creates a perception of stigma among patients, which in turn has a negative impact on their social relationships.

There were a striking number of very significant correlations between the individual variables (attribution of personality problems, alienation, management strategies, low social satisfaction/interaction and strong social/emotional loneliness), as well as a significant correlation of number of doctors and perceived attribution of personality problems on the part of the patients.

This illustrates the negative spiral in which sufferers are often caught. Since the variables described above are all strongly correlated, one phenomenon often leads to the next. Thus, a chain reaction is triggered, which makes the patients plunge deeper and deeper into misery. If a person seeks help for their physical pain, but is told by their doctor that the symptoms are just in their head, they will feel misunderstood and seek more doctors, bringing them closer to the risk of being pigeonholed as a "hypochondriac" (Lennon et al. 1989). The feeling of complete helplessness, disconnection and otherness then in turn affects social life. The person may have difficulty reaching out to others, engaging with someone, opening up in relationships, let alone feeling comfortable (Mohr et al. 2011). Indeed, if she has the impression that other people attribute her physical complaints to personal weaknesses, psychiatric problems or her vulnerability, she will be alienated to the highest degree. She may feel incapable, macular, ashamed or guilty, doubtful and question herself. In addition, she may be sceptical or suspicious of others and will avoid social interactions on principle. The reduction in social contact will lead to less satisfaction with social life and ultimately with oneself (Charmaz 1983). Finally, it can be assumed that self-perception, one's own self-esteem as well as self-confidence and self-awareness are strongly influenced by the factors described. In this context, it would be exciting to conduct targeted research on these psychological aspects.

In any case, the loneliness can cause inner emptiness in the person and in turn generate further feelings of stigmatisation. The physical and emotional pain further marginalises the person and so the game starts all over again.

At best, the study of this thesis has shown that TMD patients still feel stigmatised because of their dysfunction in 2019 - exactly 30 years after the first study by Lennon (1989). This is clearly distressing. However, what is actually new about this work is the realisation that a hitherto little-noticed patient group, namely that of the largely unknown Eagle syndrome, also suffers from stigmatisation as well as an associated reduced quality of social life. The current study has thus for the first time uncovered socio-psychological aspects of this syndrome that have not yet been investigated.

So what to do with this realisation?

The fact that temporomandibular dysfunction symptoms are difficult to treat, especially since they can have psychological triggers, is already known from numerous studies - as explained in detail in the first part. It is therefore advisable to educate TMD patients with a lot of understanding and sensitivity about the possible reasons and causes of these symptoms so that they feel well cared for medically. It is important that patients feel taken seriously. This may prevent clinical labelling, the perception of a stigma, and a complicated, costly course of therapy. Furthermore, communication between several professional groups would of course be desirable to facilitate cooperation (Mohr et al. 2011). It is advisable to take measures that could contribute to reducing the discomfort of those affected. This has also been published in many scientific journals: specialised physiotherapies, accompanying psychotherapeutic measures and education are important here. Apart from that, self-help groups/forums are certainly a good idea.

Now, however, the question rather arises as to what use the thesis theory just proven is supposed to have in relation to Eagle syndrome.

<u>It starts with the diagnosis:</u>

Eagle's syndrome is to be treated with caution because of its unusual organic change at the base of the skull (the elongated bony processes), but it is not difficult to diagnose in the first instance.

For example, simple imaging procedures (panoramic X-ray, CT scans with contrast medium) can already be used to find out whether there is an overlong calcification in the temporal and hyoid bone area (Bouzaïdi et al. 2013). If there is pressure sensitivity in the neuralgic area of the jaw angle on manual palpation, the first suspicion can be raised. If, in addition, the images match the symptoms described by the patient, a reliable diagnosis can be made very quickly - *theoretically.*

The only prerequisite is the knowledge of the doctor. This is where the first hurdle lies. Due to the unusual nature and rarity of the disease, very few doctors are aware of this syndrome. This is not a reproach to the medical profession, as the reason for this can already be found in medical training. There is hardly anything about this disease in any (anatomy) textbook. This fact leads to doctors not being able to correctly classify the described symptoms of their patients and consequently not being able to make a correct diagnosis. As a result, countless medical specialists are consulted by the patients, huge amounts of money are spent, the doctor-patient relationship is strained and there is great suffering and frustration on both sides. This leads to aimless examinations, delays in diagnosis for years, pain lasting for years for those affected, severe chronicity of the pain, limitations of the patients in their everyday lives and a massively worsened quality of life. In short: serious problems arise that could possibly be prevented.

Only how?

Educational work and public campaigns would be required here. Once doctors know about the existence of Eagle syndrome, the right measures can be initiated more quickly and a possible cure for those affected can be brought about. Although it is known that the syndrome is precarious to treat due to the bony mutation at the base of the skull (Von Piekartz 2015; Ceylan 2008), (this is also shown by the high number of unsuccessful surgical interventions performed on the test persons in this study), there is still the possibility of freedom from symptoms under certain conditions. If the nerve damage caused by the ossified tendons/overlong bones is not too advanced, irreversible injury to the cranial nerves/muscles can be avoided. The shorter the bones exert pressure on the nerves, the less damage is likely to occur. Thus, the time until diagnosis is essential.

As far as we know today, nerves can regenerate relatively well - it just takes a long time and the problem is that much of this complex anatomical area of the neck has not yet been researched in detail (Prof. Dr. Harry von Piekartz - personal communication 2017-2019).

If some money were invested in research into this niche clinical area, the different methods of bone removal could be further refined so that as little secondary damage as possible occurs after the operations. In addition, special manual and physiotherapeutic treatments could be developed before and after or instead of the operations. Based on the patients' statements and their own experience, it can be said that the removal of the bones alone does not automatically guarantee immediate freedom from pain (according to Prof. Dr. Harry von Piekartz). The cranial nerves in this area are often no longer functional or incorrectly programmed due to the long-lasting pressure from the bones and continue to send pain stimuli to the brain even though the trigger (the bones) is no longer present. Therefore, the nerves are still partially impaired in their function after the bone resection. It is not uncommon for neuropathies to be present and pain to persist (n. Prof. Dr. Harry von Piekartz). To put it simply, this phenomenon can be compared to an amputation, in which phantom pain often occurs even after the pain-causing limbs have been removed. In addition, however, the newly formed scars can also trigger pain (n. Prof. Dr. Harry von Piekartz- personal communication 2017-2019).

Of course, the resignation and disillusionment of patients who accept the dangerous operations is particularly great afterwards. If the healing attempt is unsuccessful, those affected may even be more desperate than before, as all efforts seem to have been in vain.

Apart from the neuropathy caused by the bones, it should also be noted that surgical interventions involve deep cuts in this extremely sensitive, important area of the neck. The incisions result in a change in the neck structures (dead/undersupplied tissue or severed small nerves). If the scar tissue is hardened and not well supplied with blood, this can again have a negative effect on the nerves in the area (neurogenic component) (according to Prof. Dr. Harry von Piekartz). But it is precisely those nerves and muscles that run there that are so important for basal human mechanisms such as swallowing, speaking, facial-head-jaw-neck and tongue mobility, etc., as well as the autonomic nervous system. and the autonomic nervous system. Therefore, if the scars do not heal well, there will be sticky connective tissue and tense fasciae, which can result in serious neuromuscular, nervous dysfunctions (according to Prof. Dr. Harry von Piekartz). In addition, the surgical area is prone to inflammation. If those patients in whom scar healing is not optimal are not properly cared for after the operations, the daring attempt at healing by means of surgery can fail.

In summary, it can be said that it is primarily important not to let a lot of time pass unnecessarily until the diagnosis is made. This does not mean that every time a patient with a severe sore throat visits a doctor, a referral to an X-ray institute should be written immediately. Most complaints in the ear, nose and throat area are due to harmless infections that soon disappear. However, if the inflammation persists for a longer period of time despite medication and the affected person still complains about the diffuse symptoms, the possibility of nerve compression due to excess bone substance should be considered by the doctor. This is especially important as the number of unreported cases of the disease is not known (n. Prof. Dr. Harry von Piekartz). Eagle's syndrome is described as having a low incidence rate (0.16%), but it is not known how many people actually suffer from it and may remain undiagnosed throughout their lives.

If several professional fields network and interdisciplinary cooperation between ENTs, orthodontists, dentists, sports physicians and surgeons takes place, the time to diagnosis can be shortened considerably and fewer hopeless people are groping in the dark (n. Prof. Dr. Harry von Piekartz). Pain chronification and all the associated factors such as the high number of doctors, the high costs, clinical labelling, stigmatisation, loneliness and strained social relationships could be prevented.

If there is also good communication with alternative doctors, chiropractors, trained physiotherapists, osteopaths and speech therapists, it is increasingly likely that those affected will be free of symptoms.

If one takes into account the fact that the majority of the patients in the study have a very good education and many are highly qualified, but cannot work because of their pain, it also becomes clear that an improvement in their health condition would also mean an improvement for other institutions. If these people become healthy again, they are also able to work again and are economically productive, which means a considerable financial relief for health insurance companies and insurances (thus the state). The suffering of the sick would be considerably reduced and the quality of life significantly increased. Medical staff in doctors' surgeries and hospitals would be saved work and effort. If patients had to spend less money on examinations, they could afford other things, which in turn would be beneficial for the economy.

Therefore, it remains to be said that educational policy initiatives to inform prospective medical students about Eagle syndrome would be a very good approach to changing the current situation. In addition, public relations and media campaigns would be highly desirable to inform practising physicians about it as well. If all the conditions are met, this disease might soon be easily curable.

7.1 Significance for research

The special feature of this first study to investigate socio-psychological aspects of the two diseases lies in its large demographic expansion across 5 continents of the world. The aim of the work was to shed light on the difficulties and challenges faced by the patients of both groups from the perspective of the chronically ill persons and thus to generate more (social) acceptance. Perhaps through educational work as well as changed clinical approaches, an improvement can be brought about for all involved.

At this point it should be mentioned that the research question of this thesis does not raise the question of guilt (neither for the patients themselves, nor for the relatives or the medical staff). By answering the research question, at most the proven stigmatising quality of the two diseases is shown, which results from the factors described. The aim of this study was to show the field of tension in which the respective parties (sufferers, family and friends, doctors) find themselves, as well as to bring about an all-encompassing understanding of the suffering of those affected by both diseases (Eagle's syndrome and temporomandibular dysfunction). A particularly important motive of this study was to increase awareness of the rare disease "Eagle syndrome" in order to promote research in this field and to achieve possible pain relief for those affected.

Limits of the study

The question on nationalities could have been better formulated in the questionnaire to document in more detail from which federal (state), for example, American-, Asian- or Australian-born participants come.

The information on the years of pain duration could have been divided differently, as the numbers overlap in two answers. Nevertheless, the answers on the duration of pain can be considered accurate, as the participants could choose which category they felt they belonged to.

Outlook for further research questions

The conclusive results give rise to numerous new relevant questions, such as: What quality of life do Eagle syndrome patients have due to the restricted social life and the strongly perceived loneliness? To what extent does the perceived branding affect the self-esteem of those affected? Do Eagle syndrome patients tend to have anxiety disorders, panic attacks or lower stress resistance because of their perceived stigmatisation and alienation?

The field is far from exhausted in this respect. However, this thesis provides the first profound documentation on this.

8 Bibliography:

Barsky, A.J.; Klerman, G.L. (1983). Overview: hypochondriasis, bodily complaints and somatic styles. *American Journal of Psychiatry 140*, 273.

Baugh, RF.; Stocks, RM. (1993). Eagle's syndrome: a reappraisal. *Ear Nose Throat J 72*, 341-344.

Bell, W.E. (1989). *Orofacial Pains: Classification, Diagnosis, Management*, 4th edn., 101, Chicago, IL: Year Book Medical Publishers.

Blackett, JW.; Ferraro, DJ.; Stephens, JJ. (2012). Trigeminal neuralgia post-styloidectomy in eagle syndrome: a case report. *J Med Case Rep 6*, 333.

Bouzaïdi, K.; Daghfous, A.; Fourati, E.; Kechaou, I.; Jabnoun, F.; Chtioui, I. (2013). Eagle's syndrome. *Acta Radiologica Short Reports 2*, 5.

Carson, JW.; Keefe, FJ.; Lynch, TR.; Carson, KM.; Goli, V.; Fras, AM.; Thorp, SR. (2005). Loving-kindness meditation for chronic low back pain: results from a pilot trial. *J Holistic Nurs. 23*(3), 287-304.

Ceylan, A.; Köybasioglu, A.; Celenk, F. (2008). Surgical treatment of elongated styloid process: *Experience of 61 cases. Skull Base.*

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness 5*, 168-195. doi:10.1111/1467-9566.ep10491512.

De Andrade, KM.; Rodrigues, CA.; Watanabe, PC.; Mazzetto, MO. (2012). Styloid process elongation and calcification in subjects with tmd: clinical and radiographic aspects. *Braz Dent J. 23*, 443–450.

De Jong Gierveld, J.; Van Tilburg, TG. (2006). A six-item scale for overall, emotional and social loneliness: confirmative tests on new survey data. *Res Aging 28*, 582–598. doi: 10.1177/0164027506289723.

Dionne, R.; Newton-John, T.; Zakrzewska, JM. (2009). Overall management of facial pain. In: Zakrzewska, JM. (Hrsg.). *Orofacial Pain.* New York: Oxford University Press.

Drangsholt, M.; LeResche, L. (2009). Epidemiology of orofacial pain. In: Zakrzewska, JM. (Hrsg.). *Orofacial Pain.* New York: Oxford University Press.

Eagle, WW. (1937). Elongated styloid processes: report of two cases. *Arch Otolaryngol 25*, 584–587.

Fricton, J. (2007). Myogenous temporomandibular disorders: Diagnostic and management considerations . *Dent Clin North Am 51*(1), 61 – 83 .
102

Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. *Englewood Cliffs, N.J.:* Prentice-Hall.

Griffiths, R. H. (1983). Report of the president's conference on the examination, diagnosis and management of temporomandibular disorders. *J Am Dent Assoc 106*, 75–77.

Hazaveh, M.; Hovey, R. (2018). Patient Experience of Living with Orofacial Pain: An Interpretive Phenomenological Study. *JDR Clinical & Translational Research*, *3*(3), 264–271. https://doi.org/10.1177/2380084418763317.

Hilbert, R. A. (1984). The accultural dimensions of chronic pain: flawed reality construction and the problem of meaning. *Social Problems 31*, 365-78.

Hoffman, PK.; Meier, BP.; Council, JR. (2002). A comparison of chronic pain between an urban and rural population. *J Community Health Nurs. 19*(4), 213-224.

Huskisson, EC. (1974). Measurement of pain, *Lancet 11*, 1127-1131.

Ilguy, M.; Ilguy, D.; Guler, N.; Bayirli, G. (2005). Incidence of the type and calcification patterns in patients with elongated styloid process. *Journal of International Medical Research 33*(1), 96-102.

Jones, E. E.; Farina, A.; Hastorf, A. H.; et al. *(*1984). *Social Stigma.* New York: W. H.

Freeman.
Kosinski, MR.; Schein, JR.; Vallow, SM.; Ascher, S.; Harte, C.; Shikiar, R.; Frank L.; Margolis, MK.; Vorsanger, G. (2005). An observational study of health-related quality of life and pain outcomes in chronic low back pain patients treated with fentanyl transdermal system. *Curr Med Res Opin 21*(6), 849–862.
Kotarba, J. A. (1983). *Chronic Pain: Its Social Dimensions.* Beverly Hills, CA: Sage.
Kröner-Herwig, B. (1996). Chronischer Schmerz — Eine Gegenstandsbestimmung. In: Basler, HD.; Franz, C.; Kröner-Herwig, B.; Rehfisch, H.P.; Seemann, H. (Hrsg.). *Psychologische Schmerztherapie.* Berlin, Heidelberg, DE: Springer.
Lennon, M. C.; Link, B. G.; Marbach, J. J.; Dohrenwend, B. P. (1989). The Stigma of Chronic Facial Pain and Its Impact on Social Relationships, *Social Problems, Volume 36, Issue 2,* 117–134.
Link, B. G.; Marbach, J. J.; Lennon, M. C.. (1985). Measuring stigma in TMPDS patients. Unpublished manuscript.
Marbach, J.J.; et al. Facial pains and anxiety levels: considerations for treatment. *J Prosthet Dent,* in press.
Marbach, J.J.; Lennon, M.C.; Link, B.G. et al. (1990). *J Behav Med 13,* 583.
103
Marbach, J. J.; Lipton, J. A. (1978). Aspects of illness behavior in patients with facial pain. *The Journal of the American Dental Association, Volume 96, Issue 4, 630–638.*
Marbach, J. J.; Lipton, J. A. (1987). Biopsychosocial factors of the temporomandibular pain dysfunction syndrome: relevance to restorative dentistry. *Dental Clinics of North America 31,* 473-85.
McNeill, C. (1993). *Temperomandibular Disorders. Guidelines for Classification, Assessment and Management.* 2nd edn. 11. IL, USA: Quintessence Publishing Co.
Medlicott, MS.; Harris, SR. (2006). A systematic review of the effectiveness of exercise, manual therapy, electrotherapy, relaxation training, and biofeedback in the management of temporomandibular disorder. *Phys Ther. 86,* 955–973.
Merskey, H. (ed). (1986). Classification of chronic pain. *Pain [Suppl] 3,* 1–226.
Mohr, G.; von Piekartz, H.; Hotze, E. (2011). A qualitative study on pain experiences and pain behavior in patients with chronic facial pain [in German]. *Zeitschrift Kraniomandibuläre Funktion 3*(1), 9–28.
Molin, C.; Edman, G.; Schalling, D. (1973). Psychological studies of patients with mandibular pain dysfunction syndrome. *Swedish Dental Journal 66,* 15.
Neff, A.; Wolowski, A.; Scheutzel, P. et al. (2003). Differentielle und gemeinsame Merkmale bei Patienten mit atypischem Gesichtsschmerz und kraniomandibulärer Dysfunktion. *Mund Kiefer GesichtsChir 4,* 227–234.
Österreichische Medizinische Gesellschaft für Neuraltherapie und Regulationsforschung. (2016). *Neuraltherapie, Arbeitsbuch. Grundlagen – Untersuchungstechnik – Störfeld.* 2. Aufl. Facultas.
Parsons, Talcott. (1951). *The Social System.* New York: Free Press.
Prasad, KC.; Kamath, MP.; Reddy, KJ.; Raju, K.; Agarwal, S. (2002). Elongated styloid process (Eagle’s syndrome): a clinical study. *Journal of Oral & Maxillofacial Surgery 60*(2), 171e5.
Ryan, D.; Murtagh, Jamie T. Fernandez, Caracciolo and Gaspar. (2001). CT Findings Associated with Eagle Syndrome. *American Journal of Neuroradiology 22*(7), 1401-1402.
Salter, M.; Brooke, R. I.; Merskey, H.; Fichter, G. F.; Kapasianyk, D. H. (1983). Is the temporo-mandibular pain and dysfunction syndrome a disorder of the mind? *Pain 17,* 151-166.
Sandler, J.; Dare, C. (1970). The psychoanalytic concept of orality. *Journal of*

Psychosomatic Research 14, 211.
104
Sato, S.; Kawamura, H.; Nagasaka, H.; Motegi, K. (1997). The natural course of anterior disc displacement without reduction in temporomandibular joint: Follow - up at 6, 12, and 18 months. *J Oral Maxillofac Surg 55,* 234–238.
Schmidt, RF.; Struppler, A. (1982). *Der Schmerz - Ursachen, Diagnose, Therapie.* München, DE: Piper.
Schneider, J. W.; Conrad, P. (1986). In the closet with illness: epilepsy, stigma potential and information control. Pp. 110- 21. In: Conrad, Peter; Kern, Rochelle (Hrsg.). *The Sociology of Health and Illness.* New York: St. Martin's Press.
Sciotti, VM.; Mittak, VL.; DiMarco, L.; Ford, LM.; Plezbert, J.; Santipadri, E.; Wigglesworth J.; Ball, K. (2001). Clinical precision of myofascial trigger point location in the trapezius muscle. *Pain 93*(3), 259–266 .
Soldati, AB.; Miguelote, C.; Quero, C.; Pereira, R.; Santos, R.; Soares, C. (2013). *Arq Neuropsiquiatr. 71*(4), 265-6.
Strauss, A.L.; Glaser, B.G. (1975). *Chronic Illness and the Quality of Life.* St. Louis, C.V: Mosby.
Strauss, M.; Zohar, Y.; Laurian, N. (1985). Elongated styloid process syndrome: intraoral versus external approach for styloid surgery. *Laryngoscope* 95, 976–979.
Taheri, A.; Firouzi-Marani, S.; Khoshbin, M. (2014). Nonsurgical treatment of stylohyoid (Eagle) syndrome: a case report. *J Korean Assoc Oral Maxillofac Surg*. 40(5), 246-9.
Von Korff, M.; Ormel, J.; Keefe, FJ. et al. (1992). Grading the severity of chronic pain. *Pain 50,* 133-149.
Von Piekartz, H. J. M. (2015). *Kiefer- Gesichts- und Zervikalregion, Neuromuskuloskeletales Assessment und Behandlungsstrategien.* 2. Auflage. Stuttgart: Georg Thieme Verlag.
Wardian, J.; Robbins, D.; Wolfersteig, W.; Johnson, T.; Dustman, P. (2013). Validation of the DSSI-10 to Measure Social Support in a General Population. *Research on Social Work Practice 23,* 100-106.
Wittink, H. (2002). Chronic Pain Concepts and Definitions. In: Wittink, H.; Hoskins, Michael T. (Hrsg.). *Chronic Pain Management for Physical Therapists.* Second Edition. Boston: Butterworth and Heinemann.
Wolf, E.; Birgerstam, P.; Nilner, M.; Petersson, K. (2008). Nonspecific chronic orofacial pain: studying patient experiences and perspectives with a qualitative approach. *J Orofac Pain 22(4),* Malmö, Sweden: 349-58.
105
Wright, E. F. (2010). Manual of temporomandibular disorders / Edward F. Wright. 2nd ed. IA, USA.
Wright, E. F.; North, S. L. (2009). Management and Treatment of Temporomandibular Disorders: A Clinical Perspective. *The Journal of Manual & Manipulative Therapy 17*(4), 247–254.
Yemm, R. (1976). Neurophysiologic studies of temporomandibular joint dysfunction. *Oral Sci Rev. 7,* 31–53.
Zakrzewska, JM. (2002). Facial pain: neurological and non-neurological. *J Neurol Neurosurg Psychiatry. 72*(Suppl 2), ii27–ii32.

Links from the Web:

(http://www.apa.org/ethics/code/) (18.5.2018).
(http://www.univie.ac.at/ethikkommission/richtlinien_lang.php#onlineforschung) (17.5.2018).
(https://www.facebook.com/) (4.3.2018).
(https://www.physio-pedia.com/Numeric_Pain_Rating_Scale) (7.4.2018).
(http://www.apcrc.nhs.uk/library/knowledge_bulletins/documents/SocialIsolation&Loneliness.pdf) (5.5.2019).
(http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CHWE/Documents/Graded%20Chronic%20Pain%20Scale.pdf) (30.4.2019).
106

Graphics from the Web:

https://www.spine-health.com/conditions/neck-pain/neck-pain-eagle-syndrome (6.5.2018).
http://pocayo.com/Tutorial/topic-194/Atlas-of-Uncommon-Pain-Syndromes-35.html (5.5.2019).
https://www.researchgate.net/figure/ICA-and-its-relation-to-cranial-nerves-IXth-Xth-XIIthand-
sympathetic-chain-bracket_fig5_308882035 (6.5.2019).
http://www.hasznaltmobil.info/mmp/s/stylohyoid-ligament-ossification/ (5.5.2019).
http://www.omjournal.org/IssueText.aspx?issId=84 (6.5.2018).
https://www.peertechz.com/Otolaryngology-Rhinology/AOR-3-135.php (6.5.2018).
http://maxremedial.com/blog/2015/10/16/tmj-the-sneaky-symptom (6.5.2019).
107

9 Appendix

Declaration on honor

Ich erkläre eidesstattlich, dass ich die vorliegende Arbeit selbständig angefertigt, keine anderen als die angegebenen Hilfsmittel benutzt und alle aus ungedruckten Quellen, gedruckter Literatur oder aus dem Internet im Wortlaut oder im wesentlichen Inhalt übernommenen Formulierungen und Konzepte gemäß den Richtlinien wissenschaftlicher Arbeiten zitiert, durch Fußnoten gekennzeichnet bzw. mit genauer Quellenangabe kenntlich gemacht habe.
Ort, Datum, Unterschrift der Studierenden

Information sheet for online-recruitment

Dear women of this group!
I am a student of the University of Vienna (Austria, Europe) and I've experienced chronic pain for a long period. This is the reason why the topic lies close to my heart. At the moment I am completing my degree in Psychology. For my master thesis I am going to do an investigation in people with chronic pain. I therefore created a questionnaire. I wanted to ask you to take part in my study and to fulfill the questionnaire.
The participation is voluntary and can be abandoned when started. It will take about 10-15 minutes. All questions are formulated in English. Data is of course treated strictly anonymously and will be used for scientific purposes only. For further information you can contact me via email: nora.aigner@gmail.com

Criteria for participation:

- You are female
- You have a diagnosis of Eagle Syndrome/TMD
- You have been in pain for at least half a year & are still in pain
- You have been/are in (current) treatment or planning to do so

Please, only continue responding to this questionnaire if you meet the criteria. This questionnaire should only be filled in once. Please answer the questions in the most sincere way. Your participation could be very useful for research of health issues.
The link to my study:
https://docs.google.com/forms/d/e/1FAIpQLSeIMcd47ONSW9seGVnavA3frVAdooq18Qv015RUC9gn71Oalw/viewform?usp=sf_link

Questionnaire

In order to see the questionnaire please contact the author of the study.