



**UvA-DARE (Digital Academic Repository)**

**Improvement and care seeking for temporomandibular-pain complaints: The complexity of chronic pain**

Rollman, A.

[Link to publication](#)

*Citation for published version (APA):*

Rollman, A. (2013). *Improvement and care seeking for temporomandibular-pain complaints: The complexity of chronic pain*.

**General rights**

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

**Disclaimer/Complaints regulations**

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.



**Annemiek heeft zich gespecialiseerd in klachten van het kaakgewricht en kauwspieren (Temporomandibulaire Dysfunctie-TMD).**

Na haar studie fysiotherapie is zij zich, naast het werk in de algemene praktijk, bij het Academisch Centrum voor Tandheelkunde Amsterdam (ACTA) gaan specialiseren in de behandeling van klachten van het kaakgewricht en de kauwspieren. In dit proefschrift beschrijft zij de invloed van biopsychosociale factoren op (chronische) TMD-pijn.

Voor meer informatie ga naar [www.annemiekrollman.nl](http://www.annemiekrollman.nl)



IMPROVEMENT AND CARE SEEKING FOR TEMPOROMANDIBULAR-PAIN COMPLAINTS door Annemiek Rollman

# IMPROVEMENT AND CARE SEEKING FOR TEMPOROMANDIBULAR-PAIN COMPLAINTS

**The complexity of chronic pain**



*Annemiek Rollman*

# **Improvement and care seeking for temporomandibular-pain complaints**

**The complexity of chronic pain**

Annemiek Rollman

This thesis was prepared at the Department of Oral Function and Restorative Dentistry, Section Oral Kinesiology, of the Academic Centre for Dentistry Amsterdam (ACTA), University of Amsterdam and the Vrije Universiteit, Research Institute MOVE, Amsterdam, The Netherlands.

Printing: Gildeprint, [www.gildeprint.nl](http://www.gildeprint.nl)

Cover-design: Iris Kauffman, [www.ontwerpstyl.nl](http://www.ontwerpstyl.nl)

© 2013, Annemiek Rollman

No part of this book may be reproduced or transmitted in any form or by any means without prior permission from the author.

**Improvement and care seeking for temporomandibular-pain complaints**

**The complexity of chronic pain**

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. D.C. van den Boom

ten overstaan van een door het college voor promoties ingestelde commissie,

in het openbaar te verdedigen in de Agnietenkapel

op woensdag 27 november 2013, te 12:00 uur

door Annemiek Rollman

geboren te Amerongen

Promotiecommissie

Promotor: Prof. dr. ir. M. Naeije

Co-promotor: Dr. C.M. Visscher

Dr. R.C. Gorter

Overige leden:

Prof. P.U. Dijkstra

Prof. D. Wismeyer

Prof. M.A.J. Eijkman

Prof. J. de Lange

Dr. C. Lucas

Faculteit der Tandheelkunde

**Never give up, always let go**

De Yoga Sūtra's Van Patanjali 1.12-1.16





Chapter 1:	Introduction	Page 9
Chapter 2:	The reproducibility and responsiveness of a patient-specific approach: a new instrument in evaluation of treatment of temporomandibular disorders	Page 15
Chapter 3:	Social support in chronic pain: development and Preliminary psychometric assessment of a new instrument	Page 27
Chapter 4:	Care seeking for orofacial pain	Page 43
Chapter 5:	Why seek treatment for TMD-like pain? A study based on semi-structured interviews	Page 65
Chapter 6:	Improvement in patients with a TMD-pain report. A 6-month follow-up study	Page 83
Chapter 7:	General discussion	Page 103
Chapter 8:	Summary	Page 115
	Samenvatting	Page 121
	List of publications	Page 126
	List of presentation	Page 127
	Dankwoord	Page 129



# Chapter 1

## Introduction

Musculoskeletal disorders are characterized by pain or soreness in the muscles and/ or joints, and functional problems. Most common musculoskeletal disorders are low back and neck pain. Less common is when pain and functional problems arise from the temporomandibular joint and/ or the masticatory muscles “Temporomandibular Disorders” (TMD). TMD pain is usually mild, fluctuates over time, and aggravates during oral functions (like eating, yawning) (1, 2). The prevalence of TMD pain in adult populations is around 5-10% (3-5). It is estimated that about half of the people suffering from TMD-pain attend a health-care practitioner (6). Within The Netherlands, primary care for TMD-patients is mainly provided by specialized dentists and physiotherapists. In secondary care, TMD care is often provided by a multidisciplinary team (specialized dentists, physiotherapists and psychologists) in specialized TMD-clinics or by oral surgeons.

Nowadays, the common assumption is that pain and its resulting disability are not only influenced by somatic pathology, but by psychological and social factors as well (7). The biopsychosocial model is a commonly accepted model that illustrates the interaction between the biological origin of pain and the psychological, and social influences on this pain (8). Although most episodes of musculoskeletal pain, including TMD pain, resolve within a couple of weeks (acute pain) (9, 10), some patients have symptoms which persist for years (chronic pain) (11, 12). In chronic patients, the pain complaints last (far) beyond the normal healing time of the original tissue damage. In this subgroup of pain patients, the complaints usually become more complex, which is illustrated by the poor treatment outcome in this group. In search for pain relief, these patients may attend various health-care practitioners or receive long-lasting treatments. Subsequently, the healthcare costs for musculoskeletal pain patients are substantial (13, 14). It is assumed that especially in these chronic pain complaints psychological, and social factors play an important role (8). This is illustrated by the high level of stress, depression, somatization, anxiety and passive coping strategies that are often found in chronic pain patients (15). Better insight in how these biopsychosocial factors interact in TMD-pain patients may help to improve current treatment strategies for those with long lasting pain complaints.

To get a better understanding of the way biopsychosocial factors play a role in TMD-pain patients, in this thesis two different approaches were chosen. The first approach was to compare those who attend a health care provider for their TMD-pain complaints (care seekers) with those who do not (non-care seekers). Like for other pain conditions, most knowledge on (chronic) TMD pain is obtained in a clinical setting and therefore automatically derived from care seekers. As mentioned before, there is a considerable number of people with TMD-pain complaints who do not consult a health care practitioner (16). In other words, current knowledge on the complexity of chronic pain is largely based on a one-sided perspective (based on care seekers). The patient characteristics of non-care seekers might be well different from those who do seek care. For example, non-care seekers may have found a way to cope with the pain in such a way that they do not feel the urge to seek care. These strategies may be helpful in improving therapy for care seekers. Therefore in this thesis, differences in characteristics

between those who do not seek care for musculoskeletal pain and those who do are examined. The second approach was to compare patients who show improvement after a treatment period, to those who do not. In literature often a vicious cycle of chronic pain and a variety of biopsychosocial symptoms is described. It is suggested that as a result of pain, people avoid physical activities, reduce social activities and experience all kind of psychological symptoms like depression, somatization and anxiety, resulting in long periods of pain (17). However, follow up studies to support this assumption are scarce. Interestingly, even after a long period of pain complaints, there are still some patients who show improvement. Possibly, insight in characteristics of these people as compared to the characteristics of those in which pain complaints last could improve treatment strategies. Patients hold important factors for improvement. Therefore, the influence of biopsychosocial factors on the long-term course of TMD-pain was investigated by comparing patients who show improvement to those who do not show improvement.

To study which biopsychosocial factors are involved in care seeking behavior and in improvement of chronic pain, a questionnaire was developed that covers a wide range of potential factors. For this purpose, a variety of validated measures were available. However, for two constructs that could be of value in this line of research, measures were not suitable to use in TMD-pain. First: In low back pain, an instrument is regularly used to measure outcomes that are tailored to the individual patient, the so-called “patient specific approach” (PSA) (18). In this approach, a patient’s main complaint related to pain is measured and followed over-time. As compared to generic measurements, the PSA is better capable to measure improvement in only those complaint that are relevant to the individual patient (18). This approach may not only be a promising tool in low back pain, but also in TMD pain. Therefore, it was modified in such a manner, that it can be used as a measurement in evaluating improvement in TMD-patients (**Chapter 2**). Second, the social support that someone perceives while suffering from pain, could be of influence in care seeking, as well as in improvement of pain. However, an instrument that specifically measures social support when someone suffers from pain was not available. Therefore, the social support and pain questionnaire (SPQ) was developed to be measured in subjects with TMD-pain complaints as well as in other chronic pain conditions (**Chapter 3**). In **chapters 2 and 3** the development of these instruments and its clinometric properties are presented.

In the period 2007-2009, questionnaire that consisted of several biopsychosocial measures, including the PSA and SPQ, was allocated to a group of care seekers and non-care seekers. Participants were recruited from seven specialized dental clinics throughout The Netherlands and from community places in the same areas. In **Chapter 4** differences between non-care seekers and care seekers are described. Even though several aspects were revealed that differentiate care seekers from non-care seekers, the results indicated that closed answer questionnaire did not fully reflect the thoughts of people and the processes involved in care seeking. Perhaps, these thoughts and processes could be better grasped in the stories that patients tell. Therefore, to further reveal differences between non-care seekers and care seekers, a subsample of the care seekers and non-care seekers were invited for semi-structured interviews on this topic

**(Chapter 5).** Finally, the care seekers received a follow-up questionnaire after 6 months to investigate which factors from baseline could predict improvement. In **Chapter 6**, a prediction model for 6-months improvement is presented.

#### **SYNOPSIS:**

The aim of this thesis was to improve the understanding of the role of biopsychosocial factors in the development TMD-pain complaints and care seeking behavior. This was approached from different perspectives. First, those who did seek care for their TMD-pain complaints (care seekers) were compared to those who did not (non-care seekers). Additionally, the group of care seekers was further studied with respect to the number of care practitioners they attended. Finally, patient characteristics of patients who showed improvement (after a 6-month follow-up) were compared to those who did not improve.

## References:

1. Okeson JP. Differential diagnosis and management considerations of temporomandibular disorders. In: Okeson JP, editor. *Orofacial Pain Guidelines for assessment, diagnosis, and management*. Illinois: Quintessence; 1996. p. 113-84.
2. Visscher C. *Cervical Spinal Pain in Chronic Craniomandibular Pain Patients*. Amsterdam: University of Amsterdam; 2000.
3. Nilsson IM, List T, Drangsholt M. Prevalence of temporomandibular pain and subsequent dental treatment in Swedish adolescents. *Journal of orofacial pain*. 2005 Spring;19(2):144-50.
4. Goulet JP, Lavigne GJ, Lund JP. Jaw pain prevalence among French-speaking Canadians in Quebec and related symptoms of temporomandibular disorders. *Journal of dental research*. 1995 Nov;74(11):1738-44.
5. Isong U, Gansky SA, Plesh O. Temporomandibular joint and muscle disorder-type pain in U.S. adults: the National Health Interview Survey. *Journal of orofacial pain*. 2008 Fall;22(4):317-22.
6. Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Factors associated with health care seeking behaviour for orofacial pain in the general population. *Community Dent Health*. 2003 Mar;20(1):20-6.
7. Henschke N, Ostelo RW, van Tulder MW, Vlaeyen JW, Morley S, Assendelft WJ, et al. Behavioural treatment for chronic low-back pain. *Cochrane Database Syst Rev*. (7):CD002014.
8. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* (New York, NY. 1977 Apr 8;196(4286):129-36.
9. Spitzer WO, LeBlanc FE, Dupuis M. Scientific approach to the assessment and management of activity-related spinal disorders. A monograph for clinicians report of the Quebec task force on spinal disorders. *Spine*. 1987;12(7):S1-S59.
10. van Tulder M, Becker A, Bekkering T, Breen A, del Real MT, Hutchinson A, et al. Chapter 3. European guidelines for the management of acute nonspecific low back pain in primary care. *Eur Spine J*. 2006 Mar;15 Suppl 2:S169-91.
11. Carette S. Whiplash injury and chronic neck pain. *N Engl J Med*. 1994 Apr 14;330(15):1083-4.
12. Hestbaek L, Leboeuf-Yde C, Engberg M, Lauritzen T, Bruun NH, Manniche C. The course of low back pain in a general population. Results from a 5-year prospective study. *J Manipulative Physiol Ther*. 2003 May;26(4):213-9.

13. Gatchel RJ, Mayer TG, Theodore BR. The pain disability questionnaire: relationship to one-year functional and psychosocial rehabilitation outcomes. *J Occup Rehabil.* 2006 Mar;16(1):75-94.
14. Lambeek LC, van Tulder MW, Swinkels IC, Koppes LL, Anema JR, van Mechelen W. The trend in total cost of back pain in The Netherlands in the period 2002 to 2007. *Spine (Phila Pa 1976).* Jun;36(13):1050-8.
15. Dworkin SF, Massoth DL. Temporomandibular disorders and chronic pain: disease or illness? *J Prosthet Dent.* 1994 Jul;72(1):29-38.
16. Locker D. The symptom iceberg in dentistry. Treatment-seeking in relation to oral and facial pain. *J Can Dent Assoc.* 1988 Apr;54(4):271-4.
17. Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain.* 2000 Apr;85(3):317-32.
18. Beurskens AJ, de Vet HC, Koke AJ, Lindeman E, van der Heijden GJ, Regtop W, et al. A patient-specific approach for measuring functional status in low back pain. *J Manipulative Physiol Ther* 1999;22:144-148.



## **Chapter 2**

### **The reproducibility and responsiveness of a Patient Specific Approach: A new instrument in TMD-treatment evaluation**

**A. Rollman, M. Naeije, C.M. Visscher**

## Abstract

In low-back pain patients, a 'Patient Specific Approach' (PSA) is introduced to evaluate treatment effect. In this approach, the patient is asked to choose, from the activities that are impaired, the activity which is most important in daily life. Aims: To evaluate the choices of activities on the PSA in a sample of TMD patients and to determine the clinimetric properties of the VAS scores of the PSA, in terms of reproducibility and responsiveness were determined. Methods: At treatment start, TMD patients reported the PSA-activity which is impaired due to their TMD complaints. The amount of hindrance during this activity was rated on a Visual Analogue Scale (VAS). During two follow-up measurements, patients rated the VAS and appraised their overall complaints in terms of 'much worsened', 'slightly worsened', 'remained stable', 'slightly improved', or 'much improved'. Results: Of the 132 patients who fulfilled baseline measurements, 13% reported an activity that is not included in existing TMD-disability questionnaires. The reproducibility of the VAS scores of the 78 patients who reported that their complaints had 'remained stable' at second measurement, was good (ICC=0.73). The responsiveness of the PSA was high (AUC=0.91), and the cutoff score for important improvement, where sensitivity (0.85) and specificity (0.84) were as much as possible the same was 58%. Conclusion: The PSA for TMD patients is a new and easy-to-use tool in treatment evaluation. Moreover, the VAS score of the PSA has good reproducibility and responsiveness.

**Key words:** Patient Specific Approach, TMD, treatment effect, reproducibility, responsiveness

## Introduction

Musculoskeletal disorders are characterized by pain and dysfunction (1-3). Traditionally, success of treatment in these disorders is measured with physical findings like range of motion, muscle pain and muscle strength. Nowadays, patients' self-report on the relief of complaints is considered to be increasingly important in medical decision making and determining the success of treatment (4).

One way to measure complaints is by the use of questionnaires. For example, functional (dis-) abilities can be evaluated by disorder-specific questionnaires, such as the Oswestry Low Back Pain Disability Questionnaire (5) or the Neck Disability Index (6). For Temporomandibular Disorders (TMD), amongst others the Mandibular Function Impairment Questionnaire (MFIQ) and the Jaw Disability Index (JDI) can be used to measure disability in functions like chewing and yawning (7, 8). A consequence of using this type of questionnaires is that the activity that is of greatest importance to the patient, may not be included in the questionnaire. To overcome this problem, in the treatment of low-back pain patients, a measure is introduced that is tailored to the patient's specific complaints (9, 10). In this 'Patient Specific Approach' (PSA), the patient is asked to report the most important activity that is difficult to perform because of the back pain. The amount of hindrance the patient experiences when performing this activity is measured by a Visual Analogue Scale (VAS). The change in hindrance of the activity during treatment is then used as a measure for treatment effect. Such an approach, in which improvement is measured only in the activity that is relevant to the individual patient, may not only be promising in low-back pain patients, but also in treatment evaluation of TMD patients. Therefore, the aim of this study was twofold: First, to evaluate the choice of activities on the Patient Specific Approach in a sample of TMD patients. Second, to determine the clinimetric properties of the VAS scores of the PSA, in terms of reproducibility and responsiveness.

## Materials and Methods

### Study population

Between summer 2006 and winter 2008, TMD patients from the department of Oral Kinesiology of the ACTA, were invited to participate in the study. Patients were excluded if they were aged <18 years or unable to read Dutch. Written informed consent of all participants was obtained. In total, 132 TMD-patients (114 female), with a mean age of 39 years (sd = 14), participated. Based on the Research Diagnostic Criteria (7), group I (muscle) disorder was found in 78% of these patients; group II (disc displacement) disorder was found in 35%; group III (arthralgia, arthritis, arthrosis) disorder was found in 24% of the patients. The medical ethical review board of the VU University Amsterdam approved to this study.

## Procedure

Prior to the patient's first visit to the department, as part of a routine set of questionnaires, patients received written instructions by mail regarding the use of the patient specific approach (PSA). They were asked to consider the activity that is most important and difficult to perform because of their complaints, without examples given. The dentist discussed this consideration and gave further verbal instructions on the use of the PSA at the first visit. Then, when good understanding of the PSA was achieved, the patients made a final choice on the activity that was most important to them, and the amount of hindrance performing this activity was rated on a 100mm Visual Analogue Scale (VAS). The left anchor of this VAS represents "no hindrance", and the right anchor represents "worst possible hindrance". This activity and its VAS score were considered the baseline measurement.

The participant was asked to rate the amount of hindrance again a second time (at the second visit, before treatment started) and a third time (six to eight weeks after treatment started), without insight in the earlier VAS score. Moreover, at these follow-up measurements, patients were also asked to judge whether their general TMD complaints had changed by answering the following question: *"Since my initial visit at ACTA my TMD complaints: worsened much, worsened slightly, remained stable, improved slightly, improved much"*.

## Statistical Analyses

*Reproducibility.* The baseline- and second-measurement VAS scores of those patients who reported that their TMD complaints 'remained stable' were used to calculate the Intraclass Correlation Coefficient (ICC). A two-way effects model, based on absolute agreement measures was used. The (conservative) single measure ICCs were calculated. An ICC lower than 0.40 suggests poor agreement; 0.40-0.75 fair to good agreement; >0.75-1 excellent agreement (11).

*Responsiveness.* First, Spearman's rank correlation coefficients were used to evaluate whether change in hindrance (baseline – third measurement) was associated with the amount of hindrance at baseline. The correlation coefficient was calculated both for the change in hindrance expressed in millimeters and for the relative change in hindrance expressed as a percentage of the baseline score. Then, the change in hindrance (expressed either in millimeters or as a percentage) with the lowest association with the baseline score was used in a Receiver Operating Characteristics analysis (ROC)-curve. Patients who judged their complaints as 'improved much' on third measurement were classified as 'improved', while patients who judged their complaints as 'worsened much', 'worsened slightly', 'remained stable' or 'improved slightly', were classified as 'non-improved'. In this ROC-analysis, sensitivity represents the percentage of correctly classified 'improved' patients, whereas specificity represents the percentage of correctly classified 'non-improved' patients. The ROC curve displays sensitivity versus 1-specificity rates each change in hindrance. The area under curve (AUC) can be interpreted as the

probability of correctly identifying improved patients (12). The AUC is a measure for responsiveness; an AUC of 0.50-0.70 represents low discriminative power; 0.70-0.90 moderate and >0.90 represents high discriminative power (13). From this curve, the change in hindrance where sensitivity and specificity were as much as possible the same, was considered the cutoff that best discriminates between improved and non-improved patients (9, 14, 15). This indicates that a patient that has a decrease in hindrance  $\geq$  cutoff has improved. The 95%-confidence intervals were determined using the Wilson-score method (16). The Statistical Package for Social Sciences (SPSS 16.0) was used to analyze the data ( $\alpha = 0.05$ ).

## Results

One-hundred-and-thirty-two patients completed the baseline measurement. They reported a wide variety of activities that were most important and difficult to perform to them (Table 1). Thirteen percent of the patients reported activities (relaxing, sleeping and others) that were not included in other disability questionnaires for TMD complaints (7, 8). The amount of hindrance patients experienced while performing the activities, rated on the VAS, varied widely (mean  $\pm$  standard deviation [SD]= 57; 20 mm).

**Table 1** Frequency of Patient Specific Activities Selected at Baseline (n = 132)

Activity	Frequency (%)
Eating	83 (63)
Opening mouth	14 (11)
Yawning	12 (9)
Sleeping	5 (4)
Talking	5 (4)
Relaxing	4 (3)
Others (eg, singing, playing an instrument)	9 (6)
Total	132 (100)

## Reproducibility

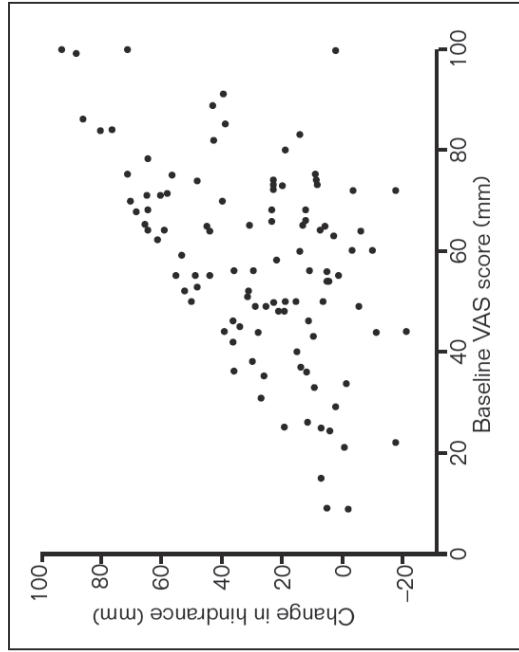
One-hundred-and twenty-three patients completed the second measurement (response rate = 93%), and 78 patients reported that their TMD complaints had 'remained stable'. They were included in the reproducibility analysis, which showed that the reproducibility of the PSA measurement was good (ICC = 0.72; 95% confidence intervals = 0.57- 0.82).

## Responsiveness

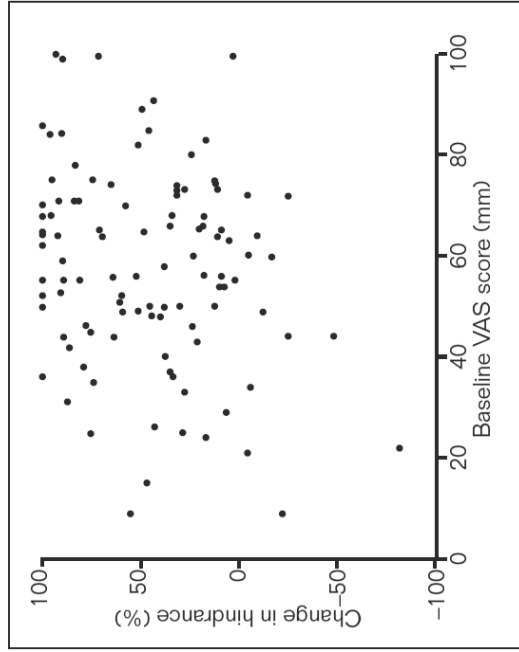
From 109 participants, also the third measurement data were collected (response rate = 83%). Forty patients judged their complaints as 'improved much' on third measurement and were classified as 'improved', while 69 patients judged their complaints as 'worsened much'(n=1), 'worsened slightly'(n=2), 'remained stable' (n=26) or 'improved slightly' (n=39), and were classified as 'non-improved'. A 64 year old woman judged her complaints as 'improved slightly', while her VAS score worsened from 9 mm on baseline measurement, to 41 mm on third measurement, which suggests that she misinterpreted the instructions. The data of this outlier were excluded from the responsiveness analysis.

Figure 1 plots the change in hindrance and Figure 2 plots the relative change in hindrance against the amount of hindrance at baseline (N = 108). While no significant association was found between the amount of hindrance at baseline and the relative change in hindrance ( $r_s = 0.15$ ;  $p = 0.12$ ), a strong association was found with the change in hindrance expressed in millimeters ( $r_s = 0.44$ ;  $p = 0.00$ ). Therefore, the relative change in hindrance was used for the ROC analysis.

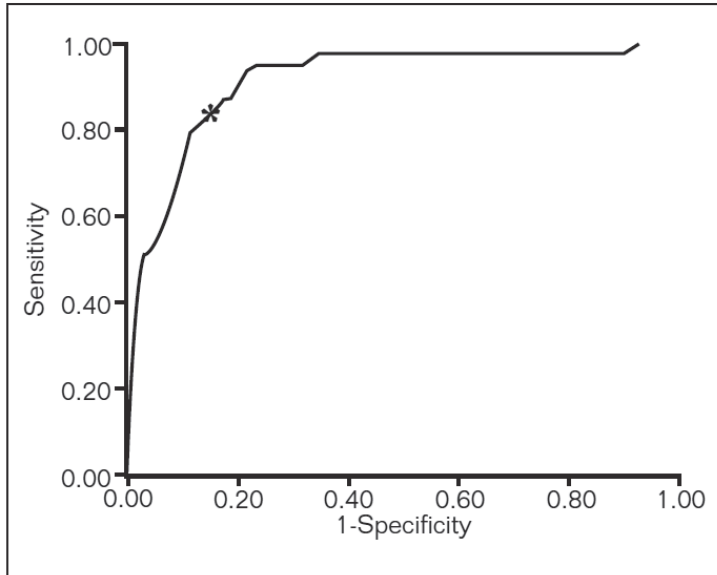
The responsiveness of the PSA, as illustrated in the ROC curve (Fig 3), was high (AUC = 0.91; 95% confidence intervals = 0.86- 0.97). A relative change of 58% was considered the optimal cutoff to discriminate between 'improved' and 'non-improved patients' (sensitivity = 0.85; 95% confidence intervals = 0.79-0.91; specificity = 0.84; 95% confidence intervals = 0.77-0.91).



**Fig 1** Scatterplots of the change in hindrance expressed in millimeters plotted against the baseline VAS scores (n = 108).



**Fig 2** Scatterplots of the relative change in hindrance expressed in millimeters plotted against the baseline VAS scores (n = 108).



**Fig 3** The ROC curve for relative change in amount of hindrance on the PSA. \* = cutoff (58%; sensitivity = 0.85; specificity = 0.84).



## Discussion

In this study, the patient specific approach (PSA) is introduced as a new instrument for TMD-treatment evaluation. It is designed to evaluate the amount of hindrance a patient perceives from the activity that is most important and difficult to perform because of his/her complaints. The concept of this patient-tailored instrument was found in low-back pain literature (9, 10). In this study, an earlier suggestion for improvement of the methods was adopted (10): of the initial two intake visits, one visit was replaced by written instructions patients received by mail.

So far, disability from mandibular activities can be measured by questionnaires like the Mandibular Function Impairment Questionnaire (MFIQ) or the Jaw Disability Index (JDI) (7, 8). In these questionnaires, the amount of disability from a predetermined list of mandibular activities is used as outcome measure. The PSA focuses on the most important activity the patient is hindered from. In this study, 13% of the patients reported an activity that is not included in the before mentioned lists. A possible weakness of the PSA may be that the patients' choice on the most important activity cannot be revised after baseline measurement. This issue has also been addressed in the low back pain literature (10). However, whether this happens and how this would influence the usefulness of the PSA is unknown. Further research is needed to explore this issue.

To determine the reproducibility, only the outcomes of those patients who indicated that their TMD complaints had not changed between the baseline and the second visit were used. The agreement between these measurements was good (it almost reached the level of excellent agreement), and is comparable to the reproducibility of the PSA in knee-dysfunction patients (17). Moreover, it is also comparable to the reproducibility found for other uses of the VAS, like for pain intensity or health-related quality of life (18, 19). To determine the responsiveness, the TMD patients were asked to rate their hindrance from the PSA again 6- 8 weeks after treatment started. At the third measurement, 40 patients showed that their complaints "improved much". The responsiveness reached the level of high discriminative power (Area Under the Curve = 0.91), and was comparable to the responsiveness found in other studies (9, 14, 15, 20, 21) (AUC = 0.80 - 0.89).

The correlation analyses showed that the change in hindrance during treatment expressed in millimeters was positively associated with the amount of hindrance at baseline. Consequently, the cutoff to recognize patients who have improved is lower for patients with a low baseline score than for patients with a high baseline score. For practical use it is preferable to use one cutoff for all patients regardless of their baseline score. Since the relative change in amount of hindrance was not associated with the amount of hindrance at baseline, this change was used as measure for treatment effect.

To be able to use the PSA in the decision to end treatment, a cutoff to recognize important improvement is needed. Therefore, the patients who judged their complaints

as “improved much” were discriminated from those who did not reach this level of improvement yet. Since, in our opinion, “to unnecessarily continue treatment” is as harmful as “to prematurely end treatment”, that cutoff was chosen for which sensitivity and specificity were the same. The estimate for the cutoff found in this study was 58% (sensitivity = 0.85; specificity = 0.84). Other studies on treatment evaluation that used pain intensity as outcome measure, found slightly lower cutoffs (47-55%) (14, 15, 20, 21).

So, the outcome of this study indicates that when a TMD patient shows a decrease in hindrance of at least 58%, a clinically important improvement is achieved. For practical reasons a cutoff of 60% can be used.

### **Conclusion**

The patient specific approach for TMD patients is a new and easy-to-use tool in treatment evaluation. Moreover, the VAS score of the patient specific approach for TMD patients has good reproducibility and responsiveness.

### **Acknowledgements**

We would like to thank all colleagues at the Department of Oral Kinesiology who facilitated this study. This study was supported by the Institute for Dental Sciences in the Netherlands (IOT).

## References

1. Feine JS, Widmer CG, Lund JP. Physical therapy: a critique. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 1997;83:123-127.
2. Ferrari R, Russell AS. Regional musculoskeletal conditions: neck pain. *Best Pract Res Clin Rheumatol* 2003;17:57-70.
3. Ostelo RW, van Tulder MW, Vlaeyen JW, Linton SJ, Morley SJ, Assendelft WJ. Behavioural treatment for chronic low-back pain. *Cochrane Database Syst Rev* 2005:CD002014.
4. Ostelo RW, de Vet HC. Clinically important outcomes in low back pain. *Best Pract Res Clin Rheumatol* 2005;19:593-607.
5. Beurskens AJ, de Vet HC, Koke AJ, van der Heijden GJ, Knipschild PG. Measuring the functional status of patients with low back pain. Assessment of the quality of four disease-specific questionnaires. *Spine* 1995;20:1017-1028.
6. Vernon H, Mior S. The Neck Disability Index: a study of reliability and validity. *J Manipulative Physiol Ther* 1991;14:409-415.
7. Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: review, criteria, examinations and specifications, critique. *J Craniomandib Disord* 1992;6:301-355.
8. Stegenga B, de Bont LG, de Leeuw R, Boering G. Assessment of mandibular function impairment associated with temporomandibular joint osteoarthritis and internal derangement. *J Ofac Pain* 1993;7:183-195.
9. Beurskens AJ, de Vet HC, Koke AJ. Responsiveness of functional status in low back pain: a comparison of different instruments. *Pain* 1996;65:71-76.
10. Beurskens AJ, de Vet HC, Koke AJ, Lindeman E, van der Heijden GJ, Regtop W, et al. A patient-specific approach for measuring functional status in low back pain. *J Manipulative Physiol Ther* 1999;22:144-148.
11. Shrout PE, Fleiss J. Intraclass correlations: uses in assessing rater reliability. *Psychological Bulletin* 1979;86:420-428.
12. Deyo RA, Centor RM. Assessing the responsiveness of functional scales to clinical change: An analogy to diagnostic test performance. *J Chronic Dis* 1986; 39: 897-906
13. Swets JA. Measuring the accuracy of diagnostic systems. *Science* 1988;240:1285-1293.

14. Farrar JT, Young JP, Jr., LaMoreaux L, Werth JL, Poole RM. Clinical importance of changes in chronic pain intensity measured on an 11-point numerical pain rating scale. *Pain* 2001;94:149-158.
15. Giraudeau B, Rozenberg S, Valat JP. Assessment of the clinically relevant change in pain for patients with sciatica. *Ann Rheum Dis* 2004;63:1180-1181.
16. Newcombe RG. Two-sided confidence intervals for the single proportion: Comparison of seven methods. *Stat Med* 1998; 17:857-872
17. Chatman AB, Hyams SP, Neel JM, Binkley JM, Stratford PW, Schomberg A, et al. The Patient-Specific Functional Scale: measurement properties in patients with knee dysfunction. *Phys Ther* 1997;77:820-829.
18. Crossley KM, Bennell KL, Cowan SM, Green S. Analysis of outcome measures for persons with patellofemoral pain: which are reliable and valid? *Arch Phys Med Rehabil* 2004;85:815-822.
19. Green C, Brazier J, Deverill M. Valuing health-related quality of life. A review of health state valuation techniques. *Pharmacoeconomics* 2000;17:151-165.
20. Lee JS, Hobden E, Stiell IG, Wells GA. Clinically important change in the visual analog scale after adequate pain control. *Acad Emerg Med* 2003;10:1128-1130.
21. ten Klooster PM, Drossaers-Bakker KW, Taal E, van de Laar MA. Patient-perceived satisfactory improvement (PPSI): interpreting meaningful change in pain from the patient's perspective. *Pain* 2006;121:151-157.

## **Chapter 3**

### **Social support in chronic pain: development and preliminary psychometric assessment of a new instrument**

**Carlijn MC van der Lugt, Annemiek Rollman, Machiel Naeije, Frank Lobbezoo, Corine M Visscher**

## Abstract

Satisfaction with social support (pain-relevant social support) may influence pain experience and behavior in chronic pain patients. Prior studies on measurement of social support, however, have been limited by the use of general, rather than of pain-specific assessment instruments. In this study, a new pain-relevant social support instrument, the Social support and Pain Questionnaire (SPQ), is presented together with an evaluation of its psychometric properties.

A literature search was performed to establish different aspects of social support. For each of the 6 aspects found, one item was selected for inclusion in the new questionnaire. The draft version of the questionnaire was field-tested. Thereafter, the psychometric properties of the SPQ were assessed in 250 orofacial pain patients. Principal component analysis (N=250) showed that the SPQ had a one-factor structure. The test-retest reliability of the SPQ (in a subsample of 54 patients) was fair to good ( $R=0.70$ ;  $p<0.000$ ). Convergent validity, as compared with a non-specific social support instrument, was good (N=140;  $R=0.54$ ;  $p<0.000$ ). The SPQ is a valid and reliable instrument, which offers the possibility to explore the patient's satisfaction with pain-related social support. With the SPQ, a useful tool to assess the influence of social support in various types of pain patients is provided.

**Keywords:** social support, satisfaction, chronic pain, oro-facial pain, questionnaire, Social support and pain Questionnaire

## Introduction

In 1948, the World Health Organization (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Within the health care system, pain is the most common reason for people to seek treatment [1]. Stimulated by the WHO-statement, and especially for chronic pain, the relation between nociception and pain is nowadays regarded limited, and psychological and social variables are acknowledged to influence pain experience and functioning [2, 3].

The influence of psychological factors on pain has been explored extensively [4, 5]. For example, factors like depression and anxiety have been shown to aggravate pain experience; positive coping abilities seem to decrease the experience of pain [4]; and persons with high job stress and low job satisfaction are more likely to report pain [6, 7].

The sociological literature on health and illness originates in Talcott Parsons’ theoretical account where he described that social factors play a role at various stages of illness and cure [8]. He suggested that in some people, a ‘sick role’ may occur when they are released from their usual role obligations by their social environment in order to take all necessary measures to get well. In this case, social support could be a foundation for the perseverance of disease. Two decades later, the operant model of chronic pain was introduced which proposed that pain behaviors and the degree of disability are influenced by environmental responses to this pain and disability-related behaviors [9]. Today, several behavioral studies have confirmed this theory. For example, spouse solicitous reactions to non-verbal pain behaviors (like limping and grimacing) of chronic pain patients may be associated with more disability in these patients [10], and negative spouse responses may be associated with higher levels of depressive symptoms [11]. Clinical studies in patients with chronic diseases have however supported the positive influence of social support on recovery and adaptation to the disease. For example, in cancer patients good social support is shown to protect them from the psychological impact of their disease [12], and chronic pain patients with supportive families reported less pain sites and pain interference and more decreases in pain intensity at a 12-month follow-up [13]. Also for other chronic pain conditions, like low back pain, the benefits as well as the possible negative effects of social support on the course and severity of the disease have been pointed out [14]. Better insight in the influence of social support on chronic pain may provide important information to improve current treatment strategies.

Most questionnaires on social support, are not specifically tailored to social support related to pain, but focus on social support in daily-life situations [15-19]. Social support associated with (chronic) pain complaints may have other characteristics and mechanisms than social support in daily life. An exception is the West Haven-Yale Multidimensional Pain Inventory (MPI) which evaluates the patient’s perception of their significant other’s responses to their pain behavior [20]. Although the MPI does concern support related to pain, it focuses on support by one person, i.e. the patient’s partner.

However, pain patients may also receive social support from others, like friends and family [21]. From the patient's point of view, it may be less important to know who gives the support, than compared to how this social support is perceived. Even more importantly, in the MPI the quantity of the spouse's reaction is recorded. However, satisfaction with social support not only depends on the quantity of the support but also on the appreciation of that support [14, 22].

To further understand the relationship between social support and pain behavior, an instrument which measures satisfaction with pain-relevant support is needed. Therefore, the aim of this study was to develop a short questionnaire that measures the satisfaction with social support related to pain, the 'Social support and Pain Questionnaire' (SPQ), and to determine the psychometric properties of the SPQ.



## Method

### Development of the SPQ

In December 2008, a literature search in the National Library of Medicine's PubMed Database was performed to social support instruments. In the search strategy, the combination of the text words "social support" (as combined term), with the words "pain" or "health" was used. All publications that introduced an instrument for measuring social support were retrieved [15-20, 23-28]. From those instruments all items related to social support were listed by the principal investigator (CL). Subsequently, in a multidisciplinary expert group (a psychologist, two physical therapists, and two dentists) items associated with the same aspects of social support were grouped. Then, it was discussed which of these aspects were specifically considered relevant for social support related to pain. For example, the size of one's network (as measured in the MOS social support survey [17]) was not considered a relevant aspect for pain-related social support. Based on consensus of the expert group the following aspects were selected: perceived support, advice, social companionship, care, reassurance, and practical support. For each aspect, the expert group phrased one item. The experts agreed that the phrasing of the items should unequivocally recognize that social support specifically related to pain is being measured and that the degree of satisfaction with that support is rated. Therefore, each item was preceded by the statement: "When I am in pain, I am satisfied with ..". Each item is rated on the following 5-point scale: (0) very dissatisfied, (1) dissatisfied, (2) neutral, (3) satisfied, and (4) very satisfied. Upon completion of the questionnaire, the six item scores are summed; the total scores can thus range from 0 to 24.

The draft version of the 6-item questionnaire was field-tested in a group of 30 orofacial pain patients from the Orofacial Pain Clinic of the Academic Centre for Dentistry Amsterdam (ACTA), and in a group of 30 controls without orofacial pain, recruited from a convenience sample of co-workers of the ACTA. The presence or absence of orofacial pain was verified by the following question: "Did you have pain in your face in the past month?". All participants were asked to comment in a free-text box whether the items were clearly formulated and relevant to pain, whether any item was redundant, and whether they had any other remarks (which provided no suggestions for improvement).

As the SPQ turned out to be a valid and reliable instrument to measure pain-related social support (see results), the SPQ was also translated into English. According to the guidelines for cross-cultural adaptation processes [29, 30], the Dutch SPQ was translated into English by a forward-backward translation procedure. The forward translation into English was performed by an officially licensed translation center: Taalcentrum-VU (for results, see Table 1). Thereafter, an independent, bilingual speaker, whose native languages were English and Dutch, performed a backward translation into Dutch. The backward translated Dutch version was compared with the original Dutch version, and showed only minor discrepancies (see *Discussion*).

## Psychometric properties of the SPQ

*Participants and procedure.* To study the psychometric properties of the SPQ, a total of 250 adult subjects with orofacial pain participated (mean age  $\pm$  SD [range] =  $41.7 \pm 14.1$  [18-81] years). Thirty-eight men and 212 women (84.8%) filled in the SPQ. These subjects were referred to the Orofacial Pain Clinic of the Academic Centre for Dentistry in Amsterdam (ACTA) (N=148) or to one of 7 participating Centers for Special Dental Care (N=102). An independent t-test was used to determine whether gender differences were present in the SPQ-total scores.

Of the participants, 94.7% reported a pain duration of more than three months and 46.7% had pain for more than three years. The average pain intensity was 5.5, using a visual analogue scale, with "0" for "no pain" and "10" for "worst imaginable pain".

To determine the test-retest reliability, ACTA patients who returned to the clinic within eight weeks after their first appointment (N=59) were invited to fill in the SPQ for a second time without insight into their first SPQ. Fifty-four of these patients participated (response rate: 92%). The mean time-interval between the test and the retest was 4 weeks. Besides explanation and advice, patients did not receive any treatment between these appointments.

To determine the convergent validity, 140 of the 148 ACTA patients also filled in a second questionnaire (response rate: 95%): the Social Support List 12-Interactions (SSL12-I) [28]. The SSL12-I was chosen because it measures social support, it has been tested in a patient group and formally been translated into Dutch, and it consists of a relatively small number of items. The SSL12-I is not specific for pain-relevant social support and its validity is satisfactory [28]. The medical ethical committee of the VU University of Amsterdam approved the study (file number 2004/166).

*Principal component analysis.* Principal component analysis with varimax rotation was performed on the six SPQ items (N=250). Items with factor loadings of at least 0.40 on the same factor were regarded to belong to the same cluster of variables [31].

*Test-retest reliability.* The test-retest reliability was estimated by calculating the Intraclass Correlation Coefficient (ICC) of the total scores on the SPQ (N=54). The statistical model specified for this study was a two-way mixed effects model, based on absolute agreement measures, where no interactions were assumed. Furthermore, because the estimation of the level of satisfaction with social support is usually based on a single measurement, the conservative single measure ICC's are presented in this paper. ICCs were interpreted according to Fleiss: ICC's < 0.4 are considered poor; 0.4-0.75 as fair-to-good; and >0.75 as excellent [32].

*Convergent validity.* The convergent validity was assessed by the Pearson Correlation Coefficient (PCC) between the total scores on the SPQ and the total scores on the SSL12-I (N=140).

SPSS 17 for Windows was used to perform all calculations ( $\alpha=0.05$ ).

## Results

The SPQ-total scores of the 250 participants ranged from 0 to 24. The mean total score was 15.4 with a standard deviation of 4.6. On a group level and based on the mean values of each item (Table 1), patients were equally satisfied with the different aspects of social support. There was no gender difference in the SPQ-total score (mean value (standard deviation) females: 15.5 (4.6), males: 15.1 (4.6);  $t=0.545$   $p=0.276$ ).

### Principal component analysis

Principal component analysis showed that the SPQ consists of a single factor; all six items contributed to this factor with a component loading above 0.8 (see Table 1).

### Test-retest reliability

The intraclass-correlation coefficient (ICC), characterizing the test-retest reliability of the total score of the SPQ, was 0.70 ( $p<0.000$ ), which qualifies as fair-to-good.

### Convergent validity

A significant correlation between satisfaction with pain-related social support (as expressed by the total score of the SPQ) and social support in general (as expressed by the total score of the SSL12-I) was found: the Pearson Correlation Coefficient was 0.54 ( $p<0.000$ ).

**Table 1.** Social support and Pain Questionnaire (SPQ). The six aspects of pain-relevant social support are each represented by one item (presented in Dutch and in English). For each item, the mean score, standard deviation and factor loading (as derived from a principal component analysis) is shown ( $n = 250$ )

Aspect	Als ik pijn heb, ben ik tevreden met...	When I'm in pain, I'm satisfied with ...	Mean values (s.d.)	Factor loading
1 Perceived support	de steun die ik krijg van mijn omgeving	the support that I get from the people around me	2.6 (0.9)	0.87
2 Advice	het advies dat ik krijg van mijn omgeving	the advice that I get from the people around me	2.4 (0.8)	0.84
3 Social companionship	de mate waarin ik de pijn kan bespreken met mijn omgeving	how much opportunity I have to discuss the pain with the people around me	2.6 (0.9)	0.87
4 Care	de mate waarin er voor mij wordt gezorgd	how much care I receive	2.7 (0.8)	0.87
5 Reassurance	de mate waarin mijn omgeving begrip toont	how much understanding the people around me show	2.6 (0.9)	0.89
6 Practical support	de praktische hulp die mijn omgeving mij geeft	the practical help people around me give	2.5 (0.9)	0.88

Five responses on each item are possible: (0) very dissatisfied, (1) dissatisfied, (2) neutral, (3) satisfied and (4) very satisfied. The scores are then summed, resulting in a total score, which can range from 0 to 24.

## Discussion

In the present study, a new pain-relevant social support instrument, the Social support and Pain Questionnaire (SPQ), was developed and its psychometric properties were determined. The results indicate that the SPQ shows good reliability and convergent validity.

### Orofacial pain as a model for chronic pain

The new instrument was validated in an orofacial-pain patient group. Most orofacial pain patients who were recruited for this study were referred for chronic temporomandibular pain (TMD-pain). TMD-pain patients share many commonalities with other chronic pain patients (e.g., low back pain, neck pain): it is a disorder of the musculoskeletal structures and, especially in chronic patients, an association with psychosocial factors (like depression and anxiety) is usually found [33, 34]. Orofacial pain is a relatively frequent pain condition, with a female predominance [35-37] (in this study 84.8% was female). No further distinction was made between different types of orofacial pain, because the type of pain (e.g. muscle or joint pain) was thought not to be relevant for the satisfaction with social support.

### Psychometric analysis

Principal component analysis can be used to uncover the underlying structure of a set of items. For the SPQ, all items contributed to the same factor, which implies that the homogeneity of the SPQ is high.

To determine the validity of a new instrument, ideally its outcomes are compared to those of an instrument that is known to measure the same concept (a gold standard). As mentioned before, however, no instrument is available that measures satisfaction with pain-related social support. Therefore, the convergent validity was determined; the degree of agreement between different measures supposed to quantify a similar (but not identical) subject [38]. Consequently, a significant, but not too high correlation coefficient is required. Even though clear recommendations for the range of such correlation coefficients are lacking, the correlation found with the measure for general social support ( $R = 0.54$ ) confirms the convergent validity of the SPQ.

The test-retest reliability of the SPQ was conducted with a maximal time-interval of 8 weeks. Although no treatment took place, at the end of their first session, patients did receive advice considering their pain condition. Moreover natural fluctuations in pain complaints and changes in social support may have occurred. Even though it is not possible to estimate the magnitude of these changes on the SPQ scores, they will have negatively influenced the results. In other words, the presented ICC-score of 0.70 may be considered as an underestimation of the true reliability of the SPQ.

## Translation into English

To make this questionnaire suitable for other applications, a forward-backward translation procedure was used to derive an English version of the SPQ. The backward translated Dutch version was compared with the original Dutch version. For some words a synonym was used and in some items, the word order was modified in comparison to the original list, without changing the meaning of the item. These minor discrepancies indicated that the translation procedure resulted in a proper English version.

## Limitations and Future directions

The aim of this study was to introduce a short questionnaire that measures satisfaction with pain-related social support. Because of the intention to introduce a short questionnaire, only one item per aspect thought relevant for social support was included, which may have limited the construction of a multi-dimensional questionnaire. The selection of relevant aspects for pain-related social support and the phrasing of the subsequent items was expert driven. The psychometric analysis presented in this paper provides initial support of the validity of the SPQ. However, to improve our insight in the patients' appreciation of the relevance of the specific items, future studies could further explore the psychometric properties of the SPQ. For example, ratings of item relevance by content experts (including 'expert-patients') could be explored [39], and item-impact calculations could be performed [40]. Moreover, it has been suggested that qualitative methods are needed to fully understand the meaning of social support to specific patient groups [41]. We also plan to perform such a qualitative study (with semi-structured interviews of orofacial pain patients) which may provide suggestions for further improvement of the SPQ. In addition, the preliminary finding from this study that there is no gender difference in satisfaction with social support in patients who attend an orofacial pain clinic needs further attention in future studies.

Yet, the SPQ provides the opportunity to further unravel the influence of pain-relevant social support on chronic (musculoskeletal) pain. For example, it may be used to advance our understanding whether social support benefits patients and results in fewer symptoms, or whether pain behaviors are reinforced and maintained by their social consequences. Is the decision to (not) seek care for pain complaints influenced by social support? Are there any specific patient characteristics that help predict when social support is beneficial? The SPQ now makes it possible to further explore the role of pain-relevant social support in chronic-pain patients.

## **Conclusion**

The SPQ is a valid and reliable instrument, which offers the possibility to explore the patient's satisfaction with pain-related social support. With the SPQ, a useful tool to assess the influence of social support in various types of pain patients is provided.

## **Acknowledgements**

We thank Ronald Gorter for providing helpful comments on earlier versions of this manuscript. We also thank the Centers for Special Dental Care in Alkmaar, Amsterdam, Arnhem, Breda, Nijmegen, The Hague, Zwolle and all patients for participating in this study. In addition, we thank Kevin Heerema for the translation.

## References

1. Turk DC, Dworkin RH. What should be the core outcomes in chronic pain clinical trials? *Arthritis Res Ther*. 2004; 6: 151-4.
2. Klasser GD, Greene CS. The changing field of temporomandibular disorders: what dentists need to know. *J Can Dent Assoc*. 2009; 75: 49-53.
3. Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Czerniecki JM, Robinson LR. Cognitions, coping and social environment predict adjustment to phantom limb pain. *Pain*. 2002; 95: 133-42.
4. Turk DC, Okifuji A. Psychological factors in chronic pain: evolution and revolution. *J Consult Clin Psychol*. 2002; 70: 678-90.
5. Keefe FJ, Rumble ME, Scipio CD, Giordano LA, Perri LM. Psychological aspects of persistent pain: current state of the science. *J Pain*. 2004; 5: 195-211.
6. Hoogendoorn WE, van Poppel MN, Bongers PM, Koes BW, Bouter LM. Systematic review of psychosocial factors at work and private life as risk factors for back pain. *Spine*. 2000; 25: 2114-25.
7. Bongers PM, Kremer AM, ter Laak J. Are psychosocial factors, risk factors for symptoms and signs of the shoulder, elbow, or hand/wrist?: A review of the epidemiological literature. *Am J Ind Med*. 2002; 41: 315-42.
8. Parsons T. (ed) *The Social System*. Glencoe, IL, The Free Press; 1951
9. Fordyce W E. Behavioural science and chronic pain. *Postgrad Med J*. 1984; 60(710): 865-8.
10. Romano JM, Turner JA, Jensen MP, Friedman LS, Bulcroft RA, Hops H, et al. Chronic pain patient-spouse behavioral interactions predict patient disability. *Pain*. 1995; 63: 353-60.
11. Romano JM, Jensen MP, Schmaling KB, Hops H, Buchwald DS. Illness behaviors in patients with unexplained chronic fatigue are associated with significant other responses. *J Beh Med*. 2009; 32: 558-69.
12. Kornblith AB, Herndon JE 2nd, Zuckerman E, Viscoli CM, Horwitz RI, Cooper MR, et al. Social support as a buffer to the psychological impact of stressful life events in women with breast cancer. *Cancer*. 2001; 91: 443-54.
13. Jamison RN, Virts KL. The influence of family support on chronic pain. *Behav Res Ther*. 1990;28: 283-7.



14. Gil KM, Keefe FJ, Crisson JE, Van Dalfsen PJ. Social support and pain behavior. *Pain*. 1987; 29: 209-17.
15. van Sonderen E (ed). Het meten van sociale steun met de Sociale Steun Lijst - Interacties (SSL-I) en Sociale Steun Lijst - Discrepanties (SSL-D): een handleiding, in Noordelijk Centrum voor Gezondheidsvraagstukken. Groningen: Rijksuniversiteit Groningen; 1993.
16. Mitchell PH, Powell L, Blumenthal J, Norton J, Ironson G, Pitula CR, et al. A short social support measure for patients recovering from myocardial infarction: the ENRICH Social Support Inventory. *J Cardiopulm Rehabil*. 2003; 23: 398-403.
17. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991; 32: 705-14.
18. Suurmeijer TP, Doeglas DM, Briançon S, Krijnen WP, Krol B, Sanderma R, et al. The measurement of social support in the 'European Research on Incapacitating Diseases and Social Support': the development of the Social Support Questionnaire for Transactions (SSQT). *Soc Sci Med*. 1995; 40: 1221-9.
19. van den Akker-Scheek I, Stevens M, Spriensma A, van Horn JR. Groningen Orthopaedic Social Support Scale: validity and reliability. *J Adv Nurs*. 2004; 47: 57-63.
20. Kerns RD, Turk DC, Rudy TE. The West Haven-Yale Multidimensional Pain Inventory (WHYMPI). *Pain*. 1985; 23: 345-56.
21. Turner RJ, Marino F. Social support and social structure: a descriptive epidemiology. *J Health Soc Behav*. 1994; 35: 193-212.
22. Keefe FJ, Dunsmore J, Burnett R. Behavioral and cognitive-behavioral approaches to chronic pain: recent advances and future directions. *J Consult Clin Psychol*. 1992; 60: 528-36.
23. Ren XS, Skinner K, Lee A, Kazis L. Social support, social selection and self-assessed health status: results from the veterans health study in the United States. *Soc Sci Med*. 1999; 48:1721-34.
24. Wang N, Iwasaki M, Otani T, Hayashi R, Miyazaki H, Xiao L, et al. Perceived health as related to income, socio-economic status, lifestyle, and social support factors in a middle-aged Japanese. *J Epidemiol*. 2005; 15: 155-62.
25. Lopez-Martinez AE, Esteve-Zarazaga R, Ramirez-Maestre C. Perceived Social Support and Coping Responses Are Independent Variables Explaining Pain Adjustment Among Chronic Pain Patients. *J Pain*. 2008; 9: 373-9.

26. Vaglio J Jr, Conard M, Poston WS, O'Keefe J, Haddock CK, House J, Spertus JA. Testing the performance of the ENRICH Social Support Instrument in cardiac patients. *Health Qual Life Outcomes*. 2004; 2: 24.
27. Koenig HG, Westlund RE, George LK, Hughes DC, Blazer DG, Hybels C. Abbreviating the Duke Social Support Index for use in chronically ill elderly individuals. *Psychosomatics*. 1993; 34: 61-9.
28. Eijk LM van, Kempen GI, Sonderen FL van. [A short scale for measuring social support in the elderly: the SSL12-I]. *Tijdschr Gerontol Geriatr*. 1994; 25: 192-6.
29. Guillemin F, Bombardier C, Beaton DE. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol*. 1993; 46: 1417-32.
30. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*. 2000; 25: 3186-91.
31. Field A (ed). *Discovering Statistics using SPSS for Windows*. London, Sage Publications; 2000
32. Fleiss JL (ed). *Reliability of measurement. The design and analysis of clinical experiments*. New York: John Wiley & Sons; 1986.
33. Macfarlane TV, Blinkhorn AS, Davies RM, Ryan P, Worthington HV, Macfarlane GJ. Orofacial pain: just another chronic pain? Results from a population-based survey. *Pain*. 2002; 99: 453-8.
34. Dworkin SF. Perspectives on the interaction of biological, psychological and social factors in TMD. *J Am Dent Assoc* 1994; 125: 856-63.
35. Dao TT, LeResche L. Gender differences in pain. *J Orofac Pain*. 2000; 14: 169-95.
36. LeResche L. Epidemiology of temporomandibular disorders: implications for the investigation of etiologic factors. *Crit Rev Oral Biol Med*. 1997; 8: 291-305.
37. Goulet JP, Lavigne GJ, Lund JP. Jaw pain prevalence among French-speaking Canadians in Quebec and related symptoms of temporomandibular disorders. *J Dent Res*. 1995; 74: 1738-44.
38. Campbell DT, Fiske DW. Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychol Bull*. 1959; 56: 81-105.
39. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. *Res Nurs Health*. 2006; 29: 489-97.

40. Allen F, Locker D. A modified short version of the oral health impact profile for assessing health-related quality of life in edentulous adults. *Int J Prosthodont.* 2002; 15: 446-450
41. Williams P, Barclay L, Schmied V. Defining social support in context: a necessary step in improving research, intervention, and practice. *Qual Health Res.* 2004; 14: 942-60.



## **Chapter 4**

### **Care seeking for orofacial pain**

**Annemiek Rollman, Corine M. Visscher, Ronald C. Gorter,  
Machiel Naeije**

## **Abstract**

Improved insight in the motivation to seek care for orofacial pain (OFP), as well as in the reasons to continue to seek care may provide important information to enhance current treatment strategies. Aims: To determine the contribution of a wide range of factors to care-seeking behavior in orofacial pain patient, expressed as (A) the decision to seek care, and (B) the number of care practitioners attended. Methods: Subjects with orofacial pain complaints were recruited in seven TMD-clinics and from a non-clinical population sample. They received a questionnaire including a wide range of possible predictors. To study which predictive variables were associated with the decision to seek care and with the number of care practitioners attended, multiple regression models were built. Results: Two-hundred-and-three persons with OFP participated in the study. Of these participants, 169 (140 females) had visited at least one health care practitioner (care seekers), while the other 34 persons (25 females) did not (non-care seekers). The decision to seek care was not only associated with the pain intensity ( $p < 0.05$ ), but, in women, also with fear of jaw movements ( $p < 0.01$ ): women with more fear of jaw movements were more likely to seek care. Pain intensity and disability were not associated with the number of healthcare practitioners attended. Instead, the main predictors were catastrophizing ( $p = 0.004$ ) and the use of painkillers ( $p = 0.008$ ). Conclusions: Pain intensity and fear of jaw movements play an important role in the decision to seek care for OFP. The continuous search for help is associated with catastrophizing and the use of painkillers.

**Key words:** care seeking; health care utilization; predictors; orofacial pain.

## Introduction

Orofacial pain (OFP) is a common pain condition associated with the hard and soft tissues of the face and mouth. Its prevalence in the general population is approximately 13% (range 1-48%) [1]. Chronic OFP is most commonly associated with temporomandibular disorders (TMD), but may also arise from other sources such as dental origins or trigeminal neuralgia [2]. It shares features with other chronic pain conditions, including modest associations between symptom severity and physical findings, high rates of healthcare utilization, greater prevalence among women, and significant psychological distress [2].

It is estimated that only half of the people with OFP seek treatment for their complaints. Information regarding the motivation to seek care for OFP could help to improve healthcare, by better focus on the patients' needs. However, most studies that compare care seekers and non-care seekers have focused on other pain conditions, like low back pain patients. A recent review showed that especially higher disability levels and female gender play a role in care seeking for low back pain [3]. However, the impact of low back pain on someone's daily life may be well different from that of OFP, and therefore other determinants may play a role in the decision to seek care for OFP complaints. At present, only few papers [4, 5] have studied what motivates people to seek care for OFP.

Apart from the decision whether or not to attend a healthcare practitioner, care-seeking patterns of patients who utilize healthcare differ a great deal: some patients only attend one healthcare practitioner, while others continue to search for help and attend multiple providers. In a study that included patients with various chronic pain conditions (i.e., back pain, headache or TMD pain), it was found that patients with frequent healthcare use had more severe pain and more psychological distress than pain patients with less frequent use of care [6]. In the same study, however, patients who frequently used care for conditions caused by serious pathology (e.g., cancer) versus patients who frequently used care for benign conditions (e.g., aspecific low back pain) were not markedly different on measures of pain severity, worry about pain, or somatization. This illustrates the complexity of care-seeking behavior, and calls for increased attention to the patients' motivation to attend a healthcare provider. Improved insight in the patient's perspective regarding their use of healthcare may provide important information to enhance current treatment strategies, especially for those patients who are at risk to develop chronic pain complaints.

The objective of this study is to determine the contribution of a wide range of factors (like physical symptoms, psychological factors, and socio-economical aspects) to care-seeking behavior in OFP patients. In this study, care seeking is expressed as (A) the decision to seek care, and (B) the number of healthcare practitioners attended.

## **Material and Methods**

In this study, data of care seekers as well as non-care seekers were collected. Therefore, subjects were recruited among patients who attended one of seven participating centers for Temporomandibular Disorders within The Netherlands [Amsterdam (two centers), Alkmaar, Arnhem, Breda, Den Haag, Zwolle] (care seekers), and among a non-clinical population sample (care seekers and non-care seekers). The medical ethical committee of the VU University of Amsterdam approved the study (file number 2004/166).

The subjects from the TMD clinics were recruited between December 2007 and January 2009. In that period, information letters were sent to each consecutive patient who called in for a TMD referral at one of the TMD clinics. They were invited to return a short form to the principal investigator (PI: AR). This form consisted of an informed consent and of some questions regarding the in- and exclusion criteria. Those subjects who fulfilled the selection criteria and who had indicated to be willing to participate in the study then received the survey questionnaire and were asked to return these documents to the principal investigator (AR) .

The subjects from the non-clinical population sample were recruited in the summer of 2008 at public places in and around the city centers where the TMD clinics were located. Three trained interviewers randomly interviewed passers-by about the presence of OFP. Persons who reported OFP within the last month were invited to participate in the study. When they were interested, they were asked to fill in the informed consent, the form with the selection criteria and the survey questionnaire at home, and to return these documents to the principal investigator (AR).

When participants did not return the documents within three weeks, a reminder was given by mail or phone (depending on which contact data was available). If necessary, a second reminder was given after 6 weeks.



## Study design and study population

The inclusion criteria for the study population were:

- a self-report of OFP within the last month. This was verified by a positive answer on the following question: "Did you have pain in your face in the past month?";
- at least 18 years of age; and
- a good understanding of the Dutch language.

To exclude as much as possible dental pain and rare causes of OFP (e.g. neuralgias), the following exclusion criteria were adopted:

- a report of localized dental pain
- burning sensations of the tongue or mouth;
- shooting pain that is provoked by touch (like washing or shaving); or
- a diagnosis of a systemic disease (e.g. rheumatoid arthritis) or of cancer in the head or neck region.

### Predictors (Independent variables)

The survey questionnaire consisted of a wide variety of items that are possibly associated with care seeking behavior. Where available, these so-called 'predictors' were measured with validated and reproducible methods. To ascertain its user-friendliness, preparatory to the study, the survey questionnaire was evaluated in five OFP patients. Consequently, the factor income level (socio-economic domain) was deleted, because patients found it offensive. The final survey questionnaire took about 25 minutes to complete, and consisted of the following variables:

*Demographics.* Age (in years) and gender were noted.

*Pain duration.* The duration of pain was classified as: 0-3 months; 3-6 months, 6-12 months, 1-3 years, 3-10 years, or >10 years.

*Pain intensity.* The so-called 'characteristic pain intensity' (CPI) was measured according to the Research Diagnostic Criteria for TMD (RDC-TMD) [7]. For the CPI, the 0 to 10 ratings of the questions regarding 'current pain', 'worst pain in the past 6 months', and 'average pain in the past 6 months', are averaged and multiplied by 10 (range: 0-100; higher scores denote more pain).

*Pain-related disability.* The degree of disability due to the OFP was rated with the 'disability score' (DS)[7]. For the DS, 0 to 10 ratings of interferences with 'daily activities', 'social activities', and 'work/housework in the past 6 months' are averaged and multiplied by 10 (range: 0-100; higher scores denote more disability).

*Hindrance on Function.* Using the 'Patient Specific Approach' (PSA), participants reported the most important activity that was difficult to perform because of their OFP. The amount of hindrance experienced when performing this activity is measured on a 100-mm Visual Analogue Scale (range: 0-100; higher scores denote more hindrance on function) [8].

*Widespread pain.* Pain sites outside the orofacial region experienced in the past six months were marked on the body drawing of the McGill Pain Questionnaire [9]. The number of painful body sites were counted according to the method proposed by Lobbezoo et al. [10]; neck, shoulders, arms, chest, abdomen, back, and legs (range: 0-7; higher scores denote more widespread pain).

*Use of pain killers.* Participants were asked whether they currently use pain killers for their OFP (yes/no).

*Fear of jaw movements.* Participants were asked to rate to what extent they agreed with the proposition "I'm afraid that I might injure myself if I move my jaw". This was rated on a 4-point Likert scale, ranging from 'strongly disagree' (1) to 'strongly agree' (4). This item was derived from the Tampa Scale for Kinesiophobia for Temporomandibular Disorders [11](range: 1-4; higher scores denote more fear of jaw movements).

*Coping strategies.* The Pain Coping and Cognition List (PCCL) measures attributions, expectancies and cognitive coping strategies related to pain [12]. It consists of 42 items which are rated on a six-point Likert scale ranging from 'totally disagree' (1) to 'totally agree' (6), and results in a score on 4 scales: catastrophizing (range: 1-6; higher scores denote more negative thoughts about the catastrophic consequences of pain), pain coping (range: 1-6; higher scores denote the use of more strategies to cope with pain, such as diverting attention, or ignoring pain), internal pain control (range: 1-6; higher scores denote more positive expectancies about personal control over pain), and external pain control (range: 1-6; higher scores denote more positive expectancies about control over pain by medical specialists, influential others, or supernatural influences).

*Psychological distress.* Depression and somatization were measured by the Symptom Check List 90 (SCL-90) [13]. In this questionnaire, depression represents symptoms of low mood and aversion to activity (range: 16-76; higher scores denote more depression within the last month). The somatization scale assesses bodily symptoms, such as faintness and stomach upset, associated with a general feeling of physical complaints (range: 12-60; higher scores denote more somatization within the last month).

*Dental Anxiety.* The Dental Anxiety Scale (DAS) is a 4-item questionnaire scored on a five-point Likert scale, and measures fear of a visit to the dentist, and unwarranted anxiety over dental procedures. (range: 4-20; higher scores denote more anxiousness) [14, 15].

*Satisfaction with pain-related social support.* Satisfaction with social support in relation to pain was scored with the Social Support and Pain Questionnaire (SPQ). The SPQ consists

of six items on perceived satisfaction with the following social support themes: perceived support, advice, social companionship, affective support, reassurance, and practical support. Each item is scored on a 5-point Likert scale ranging from very dissatisfied (0) to very satisfied (4) (range: 0-24; higher scores denote more satisfaction with pain-related social support) [16].

*Ethnic background.* Ethnic background was established following the method of Statistics Netherlands (CBS), an organization that collects and publishes Dutch population data for research purposes and policy making. According to this method, ethnic background is determined by the country of birth of the individual and by that of his or her parents, leading to the following classification: Native Dutch (ND), Non-Native Western (NNW) and Non-Native Non-Western (NNNW) [17].

*Level of education.* The level of education was categorized in the following four groups: no education, low (primary school), middle (junior vocational education/secondary vocational education), and high (vocational colleges/university) [18].

*Employment.* Participants were asked whether they were currently employed (yes/no).

*Household situation.* Participants were asked whether they currently lived alone (yes/ no).

#### Outcome measures (Dependent variables)

*A. The decision to seek care.* The participants were classified as “non-care seekers” or “care seekers”. They were considered to be “non-care seekers” (coded as 0) when they had never sought care for their OFP complaints. When a participant had visited at least one healthcare practitioner for OFP, that participant was considered a “care seeker” (coded as 1).

*B. The number of care practitioners attended.* The number of care practitioners attended was the total number of healthcare practitioners the participant attended for the OFP complaint

#### Data analyses

T-tests and  $\chi^2$ -tests were used to determine whether differences in age, gender and place of recruitment were present between those subjects who returned the survey questionnaire and those subjects who did not.

To study which predictive variables were associated with care seeking, both for A) the decision to seek care and B) for the number of care practitioners attended, a multiple regression model was built (for the decision to seek care, logistic regression was

used, while for the number of care practitioners linear regression was used). First, single regression analyses were performed to determine the association between the various predictors and the respective outcome measure. Since a strong correlation between pain duration and the number of care practitioners attended is anticipated (circular argument), the associations between predictors and the number of care practitioners, were corrected for pain duration in the final model. Predictors that showed at least a moderate association with the outcome measure (i.e.,  $p\text{-value} \leq 0.10$ ) were entered in the multiple regression analysis. Then, the variable with the weakest association with care seeking was removed from the multiple regression model. This was repeated in a backward stepwise manner until all variables that were retained in the model showed a  $p\text{-value} \leq 0.05$ . Finally, interactions between these predictive variables and age, gender, the data-collection method (non-clinical versus TMD-clinics), and the city of recruitment were checked. In case of a significant interaction effect, stratified regression models are presented. The explained variance of the multiple regression models are expressed by Nagelkerke's  $R^2$ .

For the final multiple regression model, the assumptions for linearity (linear relation of residuals, independent observations, normal distribution of residuals, and equal standard deviations of residuals) were checked. This was done by inspection of the 'normal P-P plot of regression standardized residual' (normal distribution of residuals), and inspection of the 'scatterplot of the standardized residuals and the standardized predicted values' (linear relation of residuals and equal standard deviations of residuals). Since for all variables only 1 observation per individual was collected, the assumption of independent observations was already met.

The Hosmer and Lemeshow test was calculated as a measure of goodness of fit of the logistic regression analysis (a non-significant test outcome indicates a good fit) [19]. SPSS Statistics 17.0 was used to analyze the data.

## Results

Figure 1 shows a flowchart of the data collection for the survey questionnaires. Fifty-nine percent of the subjects who were recruited at one of the TMD clinics and who had received the survey questionnaire returned the questionnaire (129 out of 220); in the group that was recruited from the non-clinical population this percentage was 70% (112 out of 160). Persons who did not respond did not differ from the responders with respect to age ( $t=1.892$ ;  $p=0.817$ ), gender ( $\chi^2=0.002$ ;  $p=0.961$ ) and city of recruitment ( $\chi^2=0.358$ ;  $p=0.551$ ).

In total, 203 persons with OFP were included in the study. Their mean age was 40 years (SD: 16 years), and 83% was female. Most participants were recruited in Amsterdam (60%), followed by The Hague (12%), Alkmaar (8%), Arnhem (8%), Zwolle (8%) and Breda (5%). From the 74 subjects recruited from the non-clinical population who fulfilled the in- and exclusion criteria, 40 reported to have attended at least one practitioner for their OFP complaints. No differences in age and gender were found between the two groups of care seekers (age:  $t= -0.360$ ;  $p= 0.719$ , gender  $\chi^2=0.025$ ;  $p=0.874$ ) and they were subsequently analyzed as care seekers.

In total, 169 participants had visited at least one health care practitioner for their OFP complaints (care seekers), while 34 persons did report OFP but had never attended a health care practitioner for their complaints (non-care seekers). In Table 1 the descriptives of the predictors are presented for both the non-care seekers and care seekers.

### A) The decision to seek care

In Table 2, the predictive variables that showed at least a moderate association ( $p<0.10$ ) with the decision to seek care are presented. From these variables, pain intensity and fear of jaw movements were retained in the multiple regression model (not shown). Since in this multiple regression model an interaction effect between gender and fear of jaw movements was found ( $p=0.04$ ), the analysis was subsequently stratified for gender. For women, both predictors were retained in the final multiple logistic regression model, while for men no association with fear of jaw movements could be found ( $p= 0.65$ ) (Table 2).

### B) Number of care practitioners attended

In the subsample of participants that did seek care ( $n = 169$ ), the number of care practitioners attended ranged from 1 to 6 (Figure 2). Most participants visited a dentist, physical therapist or general practitioner, some visited a neurologist, oral surgeon or acupuncturist. The predictive variables that were at least moderately associated with the

number of care practitioners attended are presented in Table 3. Catastrophizing and the use of painkillers were retained in the multiple linear regression analysis (corrected for pain duration), and no interaction effects were found (Table 3). All the assumptions for linearity of the multiple regression model were met.

**Table1 Descriptives of the Predictive Variables (n = 203)**

Predictive variable	Non-care seekers (n = 34)	Care seekers (n = 169)
Age (y)	37.7 (17.3)	42.1 (14.4)
Sex		
Female	74%	82%
Pain duration		
0-3 months	15%	10%
≥ 3 < 6 months	15%	14%
≥ 6 months < 1 year	13%	14%
≥ 1 year < 3 years	22%	23%
≥ 3 years < 10 years	13%	18%
≥ 10 years	22%	21%
Pain intensity (0–100)	33.4 (18.7)	52.2 (18.4)
Pain-relevant disability (0–100)	8.4 (16.8)	25.5 (26.0)
Hindrance on function (0–100)	25.3 (25.1)	40.0 (27.6)
Widespread pain (0–7)	2.3 (2.0)	2.9 (2.2)
Use of painkillers		
Yes	13%	48%
Fear of jaw movements (1–4)	1.4 (0.9)	1.9 (1.0)
Catastrophizing (1–6)	1.8 (0.7)	2.0 (0.8)
Pain coping (1–6)	2.9 (1.0)	3.1 (1.0)
Internal pain control (1–6)	3.6 (1.0)	3.3 (1.0)
External pain control (1–6)	2.2 (0.9)	2.5 (0.9)
Depression (16–76)	24.3 (7.2)	24.4 (9.4)
Somatic complaints (12–60)	19.0 (5.0)	20.7 (7.1)
Dental Anxiety Scale (1–4)	2.0 (0.7)	2.1 (0.9)
Social support (0–24)	15.2 (3.6)	14.2 (5.3)
Ethnic background		
ND	84%	87%
NNW	16%	8%
NNNW	0%	5%
Level of education		
No	6%	2%
Low	0%	2%
Middle	48%	53%
High	46%	43%
Employment		
Yes	71%	73%
Household situation		
Living alone	32%	23%

Continuous variables are presented as mean values ( $\pm$  SD); categorical variables are presented as percentages.

**Table 2 Predictive Variables for the Decision to Seek Care (ie, Non-Care Seekers vs Care Seekers) in the Logistic Regression Analyses (n = 203)**

	Multiple regression					
	Single regression			Multiple regression		
	P	OR	95% CI	P	OR	95% CI
Pain intensity (0–100)	<.001	1.06	1.03–1.08	.011	1.07	1.02–1.13
Fear of jaw movements (1–4)	.013	1.89	1.15–3.12	NS	NS	
Use of painkillers (no/yes)	.001	6.52	2.19–19.40			
Hindrance on function (0–100)	.010	1.02	1.01–1.03			
Pain-relevant disability (0–100)	.002	1.04	1.02–1.07			
Female	.090	2.13	0.89–5.10			

The explained variance ( $R^2$ ) of the final multiple regression model was 0.31 for men and 0.33 for women. Hosmer and Lemeshow test:  $P = 0.839$  for women and  $P = .402$  for men. OR = odds ratio; 95% CI = 95% confidence interval; NS = not significant.



**Table 3 Predictive Variables for the Number of Care Practitioners Visited (n = 169)**

Predictive variables	Single regression				Multiple regression			
	B	95% CI	$\beta$	P	B	95% CI	$\beta$	P
Use of painkillers (no/yes)	0.769	0.372–1.175	0.282	< .001	0.559	0.147–0.970	0.202	.008
Catastrophizing (1–6)	0.478	0.227–0.747	0.282	< .001	0.384	0.127–0.970	0.223	.004
Pain duration	0.194	0.068–0.319	0.229	.003	0.204	0.080–0.329	0.236	.001
Pain-relevant disability (0–100)	0.018	0.011–0.026	0.351	< .001				
Pain intensity (0–100)	0.020	0.009–0.031	0.269	< .001				
Somatic complaints (12–60)	0.044	0.017–0.071	0.244	.001				
Hindrance on function (0–100)	0.011	0.003–0.019	0.226	.005				
External pain control (1–6)	0.225	–0.013–0.464	0.146	.064				
Widespread pain (0–7)	0.090	–0.015–0.195	0.131	.093				

The single and the multiple linear regression model explains factors related to the number of health care practitioners visited (multiple regression model  $R^2 = 0.18$ ). Associations are expressed in regression coefficients (B), 95% CI, and standardized regression coefficients ( $\beta$ ).

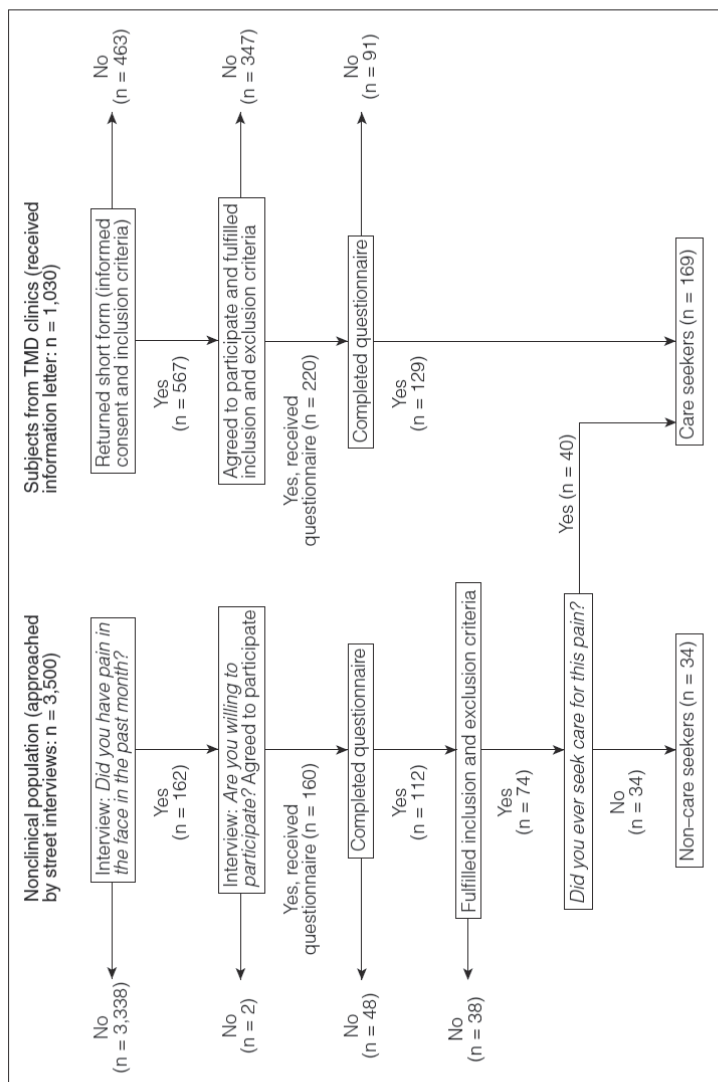


Fig 1 Flowchart of the data collection of non-care seekers and care seekers.

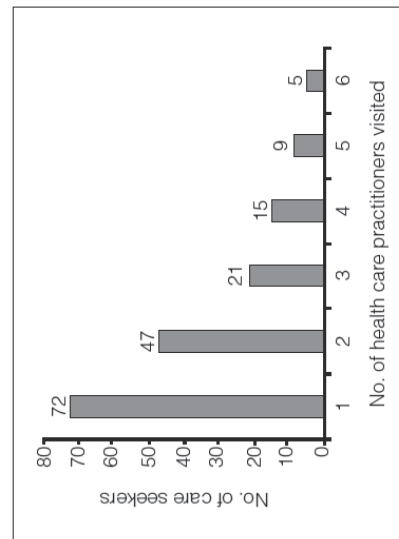


Fig 2 Number of health care practitioners visited by the 169 care seekers.

## Discussion

In this study, two aspects of care seeking behavior for OFP were investigated, namely A) factors that are related to the decision to seek care, and B) factors that are related to the number of care practitioners attended. Different factors play a role in these two aspects of care seeking behavior. The decision to seek care was associated with the intensity of the orofacial pain and with fear of jaw movements, while the number of care practitioners attended was associated with the coping strategy of catastrophizing and with the use of pain killers.

The challenge in studies to the decision to seek care is to find a control sample of persons who did not seek care for their pain. Obviously, these persons are not registered, and therefore in this study non-care seekers were recruited at public places by means of a short interview of random passers-by. This method was chosen because a face-to-face approach usually results in a higher response rate than mail or telephone surveys [20]. This was also illustrated by the higher response rate in the non-clinical population (70%) as compared to the TMD-clinic sample (almost 60%). These numbers are comparable to those found in similar study designs [5, 21]. In the recruitment at public places, also people with OFP who had sought care were found (n=40). Most of them had attended primary care practitioners (physical therapist, dentist or general practitioner) and some had seen a medical specialist (8%) or an alternative medicine practitioner (8%). They were added to the group of care seekers that was recruited in the TMD clinics. The regression analysis showed that the method of recruitment (public places or TMD clinics) did not interact with the other predictors in the models. In order to build a multiple regression model for the decision to seek care with up to 3 predictors [19], we aimed (and succeeded) to recruit at least 30 non-care seekers. The low prevalence of OFP (in this study it was approximately 5%), in combination with the observation that about half of them did not seek care, accounts for the high number of passers-by that had to be approached. Although the observed prevalence of OFP is quite lower than that found in a recent general population study (26%) [5], it is within the range of earlier findings, (1-48%) [1]. Also the percentage of persons who do not seek care for these complaints is comparable to that reported by Macfarlane (46%) [22]. "The majority of care seekers (129) were recruited in TMD clinics, while the other 40 were recruited in public places. Because of the exclusion criteria we employed to exclude dental pain as well as rare causes of OFP in both groups, we believe it is likely that most of these 169 participants were suffering from temporomandibular pain."

Since two of the participating TMD clinics were located in Amsterdam, most participants of the study were from the Amsterdam region. However, since none of the predictive factors showed an interaction effect with the city of recruitment, the results of the multiple regression analyses can probably be generalized over the various regions in the study.

#### A) The decision to seek care

This study confirmed earlier findings [5] that the decision to seek care for OFP is associated with its pain intensity ( $p < 0.05$ ), and is the first to show that, in women, the decision to seek care is also related with the scores on fear of jaw movements ( $p < 0.01$ ). The apparently low value of the OR for pain intensity (1.05 for women and 1.07 for men) is related to its measurement unit (mm). For each increase on the VAS of 1 mm a female subject is 1.05 times more likely to seek care. Recalculating the OR for a cm scale would lead to an apparently stronger OR of 1.63 for women and 1.97 for men (but with the same statistical significance).

The odds ratio of 3.20 for fear of jaw movements (Table 2) indicates that women with high scores (score = 4) show an odds for seeking help that is 33 times higher than in women with low scores on fear of jaw movements (score = 1). Further study should elaborate whether the absence of this association in men is due to the low number of male non-care seekers ( $N = 9$ ) in our study, or whether it represents a true gender difference in care seeking behavior. Because the majority of the patients that seek care for OFP are female, the role of fear of jaw movements in the decision to seek help, may open new perspectives for improving patient care.

So far, the role of fear of movement in care seeking behavior has not been investigated in other musculoskeletal pain disorders, like low back pain. Future studies should elaborate whether it plays a role in care seeking behavior in these disorders as well. In low back pain patients it was shown that disability levels were most strongly associated to care seeking behavior [3], and this is in contrast to the findings of the present study. Also when fear of jaw movements was excluded from our multiple regression model (data not shown), it was the intensity of pain which showed an association with care seeking behavior and not the level of disability. Since the majority of our OFP patients was recruited in TMD clinics, and the symptoms indicative for dental pain and more rare causes of OFP were used as exclusion criteria, most of these participants were probably suffering from a temporomandibular pain. The fact that in low-back pain and temporomandibular pain patients, different factors are associated with care seeking behavior, indicates that the impact a musculoskeletal disorder has on a patient depends on which musculoskeletal system is affected.

#### B) Number of care practitioners attended

Predictors indicative of the severity of the OFP complaint, such as pain intensity, disability and hindrance, were not independently related to the care seeking behavior of the patients, as expressed in the number of care practitioners attended. Also external pain control (i.e., positive expectancies about control over pain by medical specialists or influential others) was not retained in the multiple regression model. This is surprising and raises the question why patients are willing to attend many care practitioners when

they show no positive expectancy of the practitioner's ability to treat their pain. Maybe they have gradually lost this expectancy after having received a number of unsuccessful treatments. Instead, 'having catastrophizing thoughts' and 'the use of pain killers' showed an independent association with the shopping behavior of the patients. The finding on catastrophizing is in line with a suggestion by Turner et al [23].

It is interesting to note that two closely-related factors, i.e. fear of movement and catastrophizing, play a role in the multiple regression models for the decision to seek care and for the number of care practitioners attended. Both factors also play a key role in the fear-avoidance [24]. In this model, a vicious circle of pain, catastrophizing thoughts, fear of movement and disability, all as a reaction to a painful injury, is thought to lead to the development of chronic pain complaints. These results subscribe the relevance of an early recognition of patients' catastrophizing thoughts and fear of movement in the prevention of the development of chronic OFP.

A strong feature of this study is the wide range of predictors that were included in the survey questionnaire. Interestingly, many of the predictors thought to be relevant for care seeking behavior [3] showed no association with either the decision to seek care or the number of care practitioners attended. For example, no association was found with ethnicity, level of education, social support, or household situation. Perhaps with a larger sample size, some of the predictors could still reach the level of significance (e.g. pain-related disability). Therefore, these results are considered exploratory, and they need to be further evaluated in future studies.

In addition, the regression models only explained a small part of the care seeking behavior (for explained variance see: Table 2 and 3), indicating that other factors, not yet thought of, play an important role as well. Qualitative study designs, like those based on structured patient interviews [25], may be able to reveal these factors, important in care seeking behavior.

## **Conclusions**

This study has shown that pain intensity and fear of jaw movements play an important role in the decision to seek care for orofacial pain complaints. The continuous search for help is associated with catastrophizing thoughts and the use of pain medication.

## **Acknowledgements**

We would like to thank all colleagues at the Department of Oral Kinesiology who facilitated this study, with special appreciation to Carlijn van der Lugt and Stanimira Kalaykova for their help with the interviews of passers-by. We also thank the collaborating TMD clinics for their help in the recruitment of OFP patients: Amphia Ziekenhuis Breda, Haga Ziekenhuis Den Haag, Isala Klinieken Zwolle, Medisch Centrum Alkmaar, Stichting Bijzondere Tandheelkunde Amsterdam, and Ziekenhuis Rijnstate Arnhem. This study was supported by the Institute for Dental Sciences in the Netherlands (IOT).

## References

1. Macfarlane TV, Glenny AM, Worthington HV. Systematic review of population-based epidemiological studies of oro-facial pain. *J Dent*. 2001 Sep;29(7):451-67.
2. Fillingim RB, Wallace MR, Herbstman DM, Ribeiro-Dasilva M, Staud R. Genetic contributions to pain: a review of findings in humans. *Oral Dis*. 2008 Nov;14(8):673-82.
3. Ferreira M, Machado G, Latimer J, Maher C. Factors defining care-seeking in low back pain - A meta-analysis of population based surveys. *European Journal of Pain [Meta-analysis]*. 2010.
4. Locker D. The symptom iceberg in dentistry. Treatment-seeking in relation to oral and facial pain. *J Can Dent Assoc*. 1988 Apr;54(4):271-4..
5. Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Factors associated with health care seeking behaviour for orofacial pain in the general population. *Community Dent Health*. 2003 Mar;20(1):20-6.
6. Von Korff M, Lin EH, Fenton JJ, Saunders K. Frequency and priority of pain patients' health care use. *Clin J Pain*. 2007 Jun;23(5):400-8.
7. Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: review, criteria, examinations and specifications, critique. *J Craniomandib Disord*. 1992 Fall;6(4):301-55.
8. Rollman A, Naeije M, Visscher CM. The reproducibility and responsiveness of a patient-specific approach: a new instrument in evaluation of treatment of temporomandibular disorders. *J Orofac Pain*. 2010 Winter;24(1):101-5.
9. van der Kloot W, Vertommen H. De MPQ-DLV: Een Nederlandse versie van de McGill Pain Questionnaire. *Achtergronden en handleiding*. Lisse: Swets & Zeitlinger; 1989.
10. Lobbezoo F, Visscher CM, Naeije M. Impaired health status, sleep disorders, and pain in the craniomandibular and cervical spinal regions. *Eur J Pain*. 2004 Feb;8(1):23-30.
11. Visscher CM, Ohrbach R, van Wijk AJ, Wilkosz M, Naeije M. The Tampa Scale for Kinesiophobia for Temporomandibular Disorders (TSK-TMD). *Pain*. 2010 Sep;150(3):492-500.
12. Stomp-van den Berg SGM, Vlaeyen JWS, ter Kuile MM, Spinhoven P, van Breukelen G, Kole-Snijders AMJ. *Pijn Coping en Cognitie Lijst*. Maastricht: Pijn Kennis Centrum Maastricht; 2001.



13. Arrindell W, Ettema J. Handleiding bij een multidisciplinaire psychopathologie-indicator. Lisse: Swets & Zeitlinger; 1986.
14. Corah NL. Development of a dental anxiety scale. *J Dent Res.* 1969 Jul-Aug;48(4):596.
15. Schuurs AH, Hoogstraten J. Appraisal of dental anxiety and fear questionnaires: a review. *Community Dent Oral Epidemiol.* 1993 Dec;21(6):329-39.
16. van der Lugt C, Rollman A, Naeije M, Lobbezoo F, Visscher CM. Social support in chronic pain: development and psychometric assessment of a new instrument. Submitted. 2011.
17. van der Meulen MJ, Lobbezoo F, Aartman IH, Naeije M. Ethnic background as a factor in temporomandibular disorder complaints. *J Orofac Pain.* 2009 Winter;23(1):38-46.
18. Wijnhoven HA, de Vet HC, Picavet HS. Sex differences in consequences of musculoskeletal pain. *Spine.* 2007 May 20;32(12):1360-7.
19. Field A, editor. *Discovering Statistics Using SPSS.* 2 ed. London: SAGE Publications Ltd; 2005
20. Holbrook A, Gree M, Krosnick J. Telephone versus face-to-face interviewing of national probability samples with long questionnaires. Comparison of respondent satisficing and social desirability response bias. *Public Opinion Quarterly* Volume. [review]. 2003;67:79-124.
21. Asch DA, Jedrzejewski MK, Christakis NA. Response rates to mail surveys published in medical journals. *J Clin Epidemiol.* 1997 Oct;50(10):1129-36.
22. Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Oro-facial pain in the community: prevalence and associated impact. *Community Dent Oral Epidemiol.* 2002 Feb;30(1):52-60.
23. Turner JA, Brister H, Huggins K, Mancl L, Aaron LA, Truelove EL. Catastrophizing is associated with clinical examination findings, activity interference, and health care use among patients with temporomandibular disorders. *J Orofac Pain.* 2005 Fall;19(4):291-300.
24. Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain.* 2000 Apr;85(3):317-32.
25. Schifferdecker KE, Reed VA. Using mixed methods research in medical education: basic guidelines for researchers. *Med Educ.* 2009 Jul;43(7):637-44.



## **Chapter 5**

### **Why seek treatment for TMD-pain complaints? A study based on semi-structured interviews**

**A. Rollman, R.C. Gorter, C.M. Visscher, M. Naeije**

## **Abstract**

About half of the people with TMD-pain complaints seek treatment for their complaints. Comparing experiences and perceptions of people who seek care for TMD-pain complaints (care seekers) with people who do not (non-care seekers) can be an important source of information to improve insight in care seeking. Although questionnaire studies have highlighted some aspects that play a role in the decision to seek care (like pain intensity), much information remains unknown. Semi-structured interviews, on the other hand, allow for an open view and may reveal yet unknown aspects in care seeking. The aim of this study was to assess possible differences between care seekers and non-care seekers with TMD-pain complaints, by using semi-structured interviews. Methods: semi-structured interviews were held with 16 subjects with TMD-pain complaints: 8 care seekers and 8 non-care seekers, matched for age, sex, pain intensity and fear of movement. Subjects were selected from a previously held survey study, with their consent. The interviews were audio-taped, transcribed verbatim and analyzed according to qualitative content analysis. Results: From the analysis, seven themes differentiating care seekers from non-care seekers were identified: catastrophizing, pain management, assertiveness, critical attitude towards healthcare, confidence in medical care, recognition, and adequate referral. Conclusion: Aspects upon which care seekers differed from non-care seekers were mainly person-related characteristics. Next to these characteristics, it appeared that inadequate referrals may play a role in care seeking. Using semi-structured interviews may further improve insight in processes that determine care seeking among people with TMD pain complaints.

**Key words:** care seeking, health care practitioners, qualitative research, semi-structured interviews, temporomandibular disorder pain

## Introduction

Pain in the face or mouth (orofacial pain) is a common pain syndrome, with a prevalence of approximately 13% (range 1-48%) (1). In the acute form, it most commonly arises from a dental origin. Chronic orofacial pain is most commonly associated with a temporomandibular disorder (TMD), but may also arise from other disorders such as a trigeminal neuralgia (2, 3). Even though pain is considered the major motivational factor for individuals to seek healthcare, not all individuals experiencing pain attend a healthcare practitioner. For TMD pain, it is estimated that only about half of the people seek treatment (4, 5). Better insight in people's care seeking behavior for pain can provide essential information to further improve current treatment strategies, which is important especially for those patients who are at risk to develop chronic pain complaints (4).

In two recent studies on subjects with TMD-pain complaints, a wide range of physical, psychological, and social dimensions were measured in both non-care seekers and care seekers, explaining a variety of reasons for care seeking (6, 7). It was shown that higher levels of pain intensity increased the probability of seeking care (6, 7). Besides pain intensity, also higher levels of fear of jaw movement were positively related to care seeking (7). However, these items could only partly explain why some subjects seek care while others do not, implicating that other, still unknown aspects play an important role as well.

Since chronic TMD pain shares features with other chronic musculoskeletal pain syndromes (such as low back pain and neck pain) - including modest associations between symptom severity and physical findings, greater prevalence among women, and significant psychological distress (1, 3, 8-10), it is likely, that reasons for care seeking in subjects with TMD pain shares similarities with reasons for care seeking in subjects with other musculoskeletal pain conditions. In literature to care seeking for low back pain (LBP), it has been shown that especially physical symptoms (such as higher pain intensity and physical disability) play a role in the decision to seek care (11, 12). However, also individuals with low physical disability or only mild pain were found to have visited a healthcare practitioner, indicating that indeed other factors are involved in the decision to seek care as well (13).

Both in low-back pain and in TMD-pain studies, the common approach to study care seeking behavior is to use surveys with closed-answer questionnaires. Using semi-structured interviews invites people to speak freely about their personal pain history and may reveal yet unknown aspects that explain why some people seek care while others do not. Qualitative research designs like semi-structured interviews are powerful in discovering perceptions of people that may remain unnoticed in closed-answer questionnaire studies (14, 15). Therefore, the aim of the present study was to assess possible differences between care seekers and non-care seekers with TMD-pain complaints, by using semi-structured interviews among a selection of subjects from a previously held survey study (7).

## Material and Methods

### Subjects

The subjects in the present study were selected from a larger survey study in which 203 participants with a report of TMD pain participated, among whom were both non-care seekers and care seekers (7). Participants were considered to be “non-care seekers” when they had never sought care for their pain complaint, and “care seekers” when they had visited at least one health care practitioner for TMD-pain complaints in the past. From that study, a sample (N=16) of “non-care seekers” (N=8) and “care seekers” (N=8) was contacted by telephone by the principal investigator (AR) to invite them for a semi-structured interview, and to give informed consent (subjects had given permission to be contacted for future research in the initial survey questionnaire). Because results from the previous survey study (7) had shown that pain intensity (as measured on a characteristic pain intensity scale) (16) and fear of jaw movements (as measured with a fear-of-jaw movement scale) (7) are associated with care seeking, the non-care seekers and care seekers were matched for pain intensity and fear-of-jaw movement. Additionally, the groups were also matched for age and sex comparable to the distribution in the previous survey study (7).

### Semi-structured interviews

In alternating rounds, care seekers and non-care seekers were interviewed in a non-clinical environment: either at the participant's home, at the Oral Kinesiology department's office, or in a quiet public location, depending on the participant's preference. Each participant was interviewed for about 30–60 minutes and the interview was digitally audio taped (permission to record was given by the participant in advance). The interviews were held by the principal investigator (AR), who was trained to perform semi-structured interview techniques as described by Kvale (17).

The interviews were designed to enable people to respond in an unrestricted way, allowing aspects to be introduced by respondents and by the interviewer (18). The interviews had the following structure: an introduction in which the principle investigator gave an explanation about the goal of the interview and in which she asked the subject about his or her TMD-pain complaints (like: “How is the pain at this moment?”). After the participant was set at ease and the goal of the interview was made clear, the principle investigator asked a transition question (like: “So, could you tell about what kind of care you sought for this pain”) to bring the conversation to healthcare usage for TMD-pain complaints. Subsequently, when the participant talked about his/her care-seeking behavior, the key-question was asked: “Why did you (not) see a health care provider?”. Subjects were encouraged to describe their motivations to (not) seek treatment in their own words, by the use of open-ended questions by the

interviewer. Furthermore, in each interview, the interviewer asked the participants how each of the following topics was of influence in their care seeking:

- Pain, function limitation, limitations in daily life;
- Healthcare usage for other (pain) complaints;
- Experiences in healthcare usage (eg impression of the expertise of the health care provider);
- Practical matters (taking time off, distance to health care provider, finances);
- Knowledge of possibilities for treatment;
- Social support.

The authors chose these topics because, based on literature (6, 11, 12), it could be expected that they play a role in care seeking. To be sure that the information that was given by the participant was correctly and completely understood, the principle investigator ended the interview with a summary meanwhile inviting the participant to correct or add information if necessary.

### Saturation

The interviews of each round of matched care seekers and non-care seekers were analyzed applying the principles of the so-called constant comparative method (19), whereby data collection and analysis occur concurrently, allowing previous propositions to be explored in subsequent interviews. Using this method, data collection continued until no new issues emerged from the interviews (and saturation was achieved) (19). After interviewing 7 non-care seekers and 7 care seekers, no new information emerged. To be certain that saturation was achieved, another non-care seeker and care seeker were interviewed (Total N=16). Again, no new information emerged. Two researchers (AR and RG) were involved in this part of the analysis. AR explored the issues, which were discussed and refined with RG.

### Consensus

The audio recordings of each interview were transcribed verbatim. Then, five selected experts (a MSc in Oral Public Health and with dental education background; a psychologist specialized in social dentistry; two psychologists specialized in dentist-patient communication; and a clinical psychologist/ psychotherapist), formed a panel, and completed a consensus procedure, derived from a delphi-consensus method (20, 21). In this procedure, following a series of rounds, agreement in interpretation is achieved. In the first round, the experts were asked to individually read the interviews, without insight in the opinion of the other experts, and to denote differences between care seekers and non-care seekers. Subsequently, the principal investigator made an overview of these differences. In this overview, shared and unique observations of the

experts were categorized in a set of tentative themes. In round two, this overview was provided to each expert individually. The experts were invited to comment on the themes in two ways: First, to indicate whether the descriptions of the themes were adequate reflections of their own observations. If not, they were asked to adapt the formulation in a way that would reflect their observations better. Second, they were asked to indicate whether or not they agreed with the themes that were found by other experts. After the second round, all experts agreed to the themes, and consensus was achieved. The medical ethical committee of the VU University of Amsterdam approved the study (file number 2004/166).

## Results

As a result of the matching procedure, the 8 non-care seekers did not differ from the 8 care seekers with respect to age, gender, pain intensity and fear of jaw movements. Both in the non-care seeker group and in the care seeker group, 6 women and 2 men participated (Table 1). All participants that were invited for semi-structured interviews agreed to participate and gave informed consent.

Seven themes emerged that were considered to be different between care seekers and non-care seekers (Table 2). Six themes concerned person-related characteristics; one theme was related to external circumstances. In the following section, these themes are more fully described. Citations, illustrating the description, are written in *italic*.

### Person related characteristics

*Catastrophizing*: Care seekers interpreted their pain as alarming and too long-lasting. Care seekers appeared to be really concerned about their complaints. They considered the pain as a priority, and an argument to take time off from work: *"I went to see my general practitioner. I thought, maybe I have a brain tumor, maybe something is wrong."* [Interview 2]. Non-care seekers, on the other hand, did not consider their pain complaints as alarming and did not consider it a priority: *"Taking time off is too much hassle."* [Interview 7]. Even if pain complaints were severe, they tended to accept the situation as it is, as illustrated by the following citation: *"The pain is part of me. I read a few things about it and the pain is just part of it, and clicking will not go away. Therefore, I never considered to seek care."* [Interview 6].

*Pain Management*: Care seekers strongly believed that someone else has the solution for their pain, and, therefore, they aimed at a referral to a health care provider. *"I hoped that at an Academic TMD-centre, they would have something special which would make my pain complaints go away. A device..., or whatever..., a new joint..., something to make it normal."* [Interview 13]. Non-care seekers, on the other hand, not only had the tendency to manage their pain themselves; they were convinced that they were capable of doing



so. Some typical formulations were: *"I believe that it is something I do when I am stressed, so then I address the tension, what caused it, and I do something about it. It manifests itself here (while pointing at jaw). For someone else this may be the neck. I would first try to figure it out for myself."* [Interview 13]. Or: *"I listen to my body so I asked myself, where does the pain come from. I also chewed more chewing gum, felt I wanted that, so then I knew: hey, that is causing the pain. It increased my complaints."* [Interview 9]. Moreover, as opposed to care seekers, non-care seekers made a connection between their facial pain and personal circumstances, such as stress, or other psychological and/or physiological disturbances. Subsequently, they often came up with their own treatment strategies to relieve their pain: *"Sometimes I give my jaw a massage and I do some exercises, I know that I can help myself."* [Interview 3].

**Assertiveness:** Care seekers believed it is self-evident to seek care, and they insisted on doctors' help: *"If I have a physical complaint, most of the time I will go directly to the general practitioner."* [Interview 16]. Or: *"Although I came for a check-up at the dentist, I was the one who took the initiative to discuss my complaints."* [Interview 12]. On the other hand, non-care seekers do not want to bother someone else with their complaints. They felt uncomfortable when consulting a healthcare practitioner. Non-care seekers tended to keep the pain to themselves and did not want to complain. To them it feels like they were exaggerating when consulting a healthcare professional for their complaints: *"That's me, I don't like to whine. I know they have many patients that come for every little thing."* [Interview 15].

**Critical attitude:** Care seekers expressed criticism and were not easily satisfied with accessible care: *"Alignment between the departments is missing."* [Interview 2]. Or, *"An adequate interview was missing, no good questions."* [Interview 11]. Moreover, as a result of being critical, they were persistent in searching for adequate care. In contrast, non-care seekers did not mention this topic.

**Confidence in medical care:** Non-care seekers reported little confidence in proper treatment, and rather discussed complaints with friends in a more empathic environment. *"To check if my complaint is something serious, I use the Internet, talk to friends, but I do not go to my general practitioner. I wish I could, but there is a lack of empathy."* [Interview 2]. In contrast, care seekers did not mention this topic.

**Recognition:** Care seekers were glad to get recognition from others for their suffering, and were relieved when they had found fellow-sufferers. *"I had such vague complaints; I did not have the idea that this could have to do with my jaws. But when I came into the waiting room, I saw another guy rubbing his temples. Then I thought: I am not the only one, I'm not some kind of nutcase. I am at the right place."* [Interview 15].

**External circumstances:**

**Adequate referral:** Care seekers reported to be adequately referred to a health care provider, although often it took a long pathway to get this referral: *"After mentioning my*

*complaints to my dentist, it still took at least half a year before she pointed out this clinic to me [...] Before that, I never heard of this kind of care!"* [Interview 12]. Non-care seekers, on the other hand, reported that, although the dentist was sometimes aware of their complaints, they were not referred to a health care provider: *"My dentist knows that it hurts when I open my mouth, and that I cannot open my mouth widely. He never said anything about it. Probably, I also never discussed it explicitly with him. He never suggested any treatment."* [Interview 5].

Although it was the task of the panel of experts to reveal differences between care seekers and non-care seekers, while reading the interviews, the panel also stressed some similarities between the two groups. These similarities were: all participants used the Internet for information; most participants expressed dissatisfaction with the lack of time the general practitioner showed; and all wished that the general practitioner would have been more directive (or more quickly directive) in referring to a health care provider.

**Table 1** Description of the Participants with TMD Pain Complaints

Variable	Non-care seekers (n = 8)	Care seekers (n = 8)
Age (y)	38.9 (15.8)	37.5 (13.0)
Sex (n)		
Female	6	6
Male	2	2
Pain intensity (0–100)	46.3 (14.3)	49.4 (17.6)
Fear of jaw movements (n)		
1	0	0
2	3	3
3	5	4
4	0	1
Pain duration (n)		
0–3 mo	0	0
≥ 3 < 6 mo	1	1
≥ 6 mo < 1 y	0	0
≥ 1 y < 3 y	4	4
≥ 3 y < 10 y	0	1
≥ 10 y	3	2

Continuous variables are presented as mean values (standard deviation); categorical variables are presented as frequencies.

Table 2 Summary of the Themes Differentiating Care Seekers from Non-Care Seekers for TMD Pain Complaints			
Characteristics	No. of experts that found this theme independently (round 1)		No. of experts that found this theme independently (round 1)
	Care seeker	Non-care seeker	
Catastrophizing	Interpret their pain as alarming	Interpret their pain as not very alarming	5 out of 5
Pain management	The health care provider holds the solution; I will go and see a health care practitioner, even if it costs me money or time, because he or she can help me	Want to find the solution myself	5 out of 5
Assertiveness	Insist on health care provider's help	Do not want to bother health care practitioners with their complaints	4 out of 5
Critical attitude	Are critical and not easily satisfied about accessible care and persistent in searching for adequate care	—	4 out of 5
Confidence in medical care	—	Have little confidence in proper treatment; Rather discuss complaints with friends in a more empathic environment	4 out of 5
Recognition	Are happy to find fellow sufferers	—	1 out of 5
<b>Circumstances</b>			
Referral	Adequate	Not adequate	1 out of 5

## Discussion

The aim of the present study was to assess possible differences between care seekers and non-care seekers for TMD-pain complaints, by using semi-structured interviews. In a previous study, it was shown that pain intensity and fear of movement are related to care seeking (7). This study indicates that care seeking may also be associated with differences in person related characteristics: catastrophizing, pain management, assertiveness, critical attitude towards healthcare, confidence in medical care, and recognition. Moreover, it was found that non-care seekers are not always adequately referred to a health care provider. These results indicate that semi-structured interviews may provide further insight in processes that determine care seeking among persons with TMD-pain complaints.

In this interview study, two methodological aspects may have influenced the results. First, due to the small sample size, one runs the risk that themes that differentiate care seekers from non-care seekers were overlooked. To reduce this risk as much as possible, the constant comparative method was used (19). In this method, the data collection and data analysis occur concurrently, enabling the exploration of previous propositions in subsequent interviews. After seven pairs of non-care seekers and care seekers, no new information came up. Subsequently, an additional couple was interviewed, which did not provide new information either, suggesting that indeed saturation was achieved. A second risk is that personal notions and expectations of the experts analyzing the interviews may have influenced the results (bias). Whereas in most qualitative research studies, one or two experts analyzed the data, (18, 22, 23), in this study the risk of bias was minimized by using a Delphi-consensus method with a panel of five experts (20, 21). Four of them were psychologist, and three of these also professionally active in dentistry, thus providing for an expertise in trained listening skills to an individual's story, and familiarity with the impact of orofacial problems.

In the few qualitative research design studies to care seeking in subjects with TMD-pain complaints performed so far (18, 22, 23), the motivations and experiences of care seekers only were investigated. A unique aspect of the present study is that not only a group of care seekers, but also a group of non-care seekers was interviewed. Since non-care seekers did not report their complaints at a health care office, and therefore not registered, the recruitment of this control group is difficult. The care seekers and non-care seekers in the present study were selected from a larger survey study (7), in which about 100 people had to be approached face-to-face at public places in order to find one non-care seeker with TMD-pain complaints. Interestingly, the topics that were expected to play a role in care seeking, based upon literature, and discussed in each interview, did not fully differentiate care seekers from non-care seekers in the present study. By including a control group of non-care seekers, a better, more diverse, insight into factors influencing care seeking was obtained than when merely looking at care seekers. The fact that non-care seekers sometimes did not receive treatment for their complaints because of an inadequate referral, could only be found by interviewing non-care seekers (Table 2).

To the best of our knowledge, studies to care-seeking in subjects with TMD-pain (4, 6, 7) or low-back pain (11), including non-care seekers as a control group, always use the technique of closed-answer questionnaires. It is striking to see, that although several biopsychosocial factors were investigated, only the severity of the complaints (pain intensity, pain duration, and disability) was consistently found to be associated with the decision to seek care (4, 6, 7, 11). As the present study is most likely the first to use the technique of semi-structured interviews, participants were invited to talk freely about their personal pain history, resulting in them describing yet unknown aspects of care-seeking. Other than in questionnaire studies, the present interview study revealed that also person-related characteristics play a role in care-seeking. For example, the finding that care seekers seem critical and not easily satisfied about accessible care and persistent in searching for adequate care, was not found earlier in literature. This underlines the strong asset of in-depth interviews: it offers new information on top of what is already known from surveys. It is interesting to speculate on what exactly accounts for the differences between the standardized answering formats and a semi-structured interview format. It is possible subjects have occasionally experienced difficulties identifying themselves with the predefined phrasings, where the semi-structured interviews offered room for a personal choice of words. In this way, semi-structured interviews may have revealed characteristics that were difficult to catch in fixed formats, such as closed-answer questionnaires (24). It is encouraged that in the future, studies with a similar study-design are performed in new samples, both with regard to orofacial and other pain aspects (such as low-back pain), in order to see whether the same themes emerge.

In general, the interviews give the impression that care seekers are more focused on pain than non-care seekers. Care seekers appear more worried, and more often look for solutions externally. Possibly, as a result from expecting solutions from others, they appear assertive, critical and look for recognition. In this study we choose to separate the characteristics as different, rather broad, concepts (pain management, assertiveness, critical attitude and recognition). Future studies could give insight whether these characteristics are a consequence of the subjects' locus of control (internally or externally).

Interestingly, non-care seekers, in contrast to care seekers, appeared not so concerned about their pain (see Table 2), but nevertheless, most of them had chronic pain complaints (see Table 1). This seems to be in disagreement with the fear avoidance model by Vlaeyen et al, which suggests that catastrophizing is an important precursor of chronic pain (25). As a reaction to a painful injury, a vicious circle of pain, catastrophizing, fear of movement, and disability, are thought to lead to the development of a chronic pain condition (25). In favour of this theory is a recent clinical trial showed the therapeutic efficacy of an early biopsychosocial intervention for patients with acute TMD who are at risk of developing chronic TMD demonstrated that pain levels dropped significantly after the biopsychosocial intervention, as assessed at the one-year follow-up (26). Our findings in the non-care seeking group could just be an illustration that the fear-avoidance model is only applicable for patients, and not for

non-care seekers. Nevertheless, health-care practitioners should be aware that the care seekers who visit them for TMD-pain complaints are usually worried about the cause of their pain complaints. Therefore, reassurance should be a standard procedure in counseling patients who suffer from a TMD-pain.

Even though non-care seekers are not so worried about their pain complaints, they might suffer unnecessarily long from these complaints. They keep trying to find a solution on their own (Table 2), while treatment options may be available. Since all participants in this study reported that they searched the Internet for information, proper information on the Internet may help people to find their way to a health care provider. This suggestion is supported by an earlier report on health care seeking behavior on the Web (27), which pointed out that the information found on the Web has a direct influence on the decisions people make about their health care and also on their interactions with the health care practitioners (27). This indicates that TMD-clinics should provide the Internet with high quality, evidence-based information regarding TMD. Moreover, since this study confirmed earlier findings (22), that care seekers experience relief in finding fellow-sufferers (Table 2), patients should be facilitated to come across fellow sufferers. Possibly, and as an addition to a treatment program, group sessions of pain sufferers or Internet communities could offer a platform where patients can meet fellow sufferers. Another finding of this study is that not only person-related characteristics are of influence on the care seeking of subjects with TMD-pain complaints, also external circumstances play a role. Adequate reactions or referrals of healthcare-practitioners, when they encounter patients with TMD-pain complaints, are important. The interviews showed that a non-care seeker may be a non-care seeker because he was not adequately referred (Table 2). Moreover, and in line with a previous study (22), care seekers often expressed to have travelled a long way through the health care system before actually finding their way to a TMD health care provider. This confirms that not every healthcare provider is aware of the treatment possibilities for TMD-problems (28). As suggested by others, clear guidelines and education programs for dentists and other healthcare practitioners should be promoted, in order to increase knowledge on TMD care and TMD-treatment possibilities (29, 30).

## **Conclusion**

From this study several new themes appeared to differentiate care seekers from non-care seekers with TMD- pain complaints. Most of these themes were person related characteristics: catastrophizing, pain management, assertiveness, critical attitude towards healthcare, confidence in medical care, and recognition. Next to these characteristics, it appeared that inadequate referrals may play a role in care seeking. Using semi-structured interviews offers the possibility to increase insight in internal processes that determine care seeking among people with TMD-pain complaints.

## **Acknowledgements**

We would like to thank the collaborating TMD clinics for their help in the recruitment and follow-up of care seekers: Amphia Ziekenhuis Breda, Haga Ziekenhuis Den Haag, Isala Klinieken Zwolle, Medisch Centrum Alkmaar, Stichting Bijzondere Tandheelkunde Amsterdam, and Ziekenhuis Rijnstate Arnhem. We would like to thank all colleagues at the Department of Oral Kinesiology who facilitated this study, with special appreciation to Carlijn van der Lugt and Stanimira Kalaykova for their help with the recruitment of non-care seekers. Especially, we like to thank all participants for their participation in the research. This study was supported by the Institute for Dental Sciences in the Netherlands (IOT).



## References

1. Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Oro-facial pain in the community: prevalence and associated impact. *Community Dent Oral Epidemiol.* 2002 Feb;30(1):52-60.
2. Sessle BJ, Lavigne GJ, Lund JP, Dubner R (eds). *Orofacial Pain: From Basic Science to Clinical Management*, ed 2. Chicago: Quintessence, 2008.
3. Fillingim RB, Wallace MR, Herbstman DM, Ribeiro-Dasilva M, Staud R. Genetic contributions to pain: a review of findings in humans. *Oral Dis.* 2008 Nov;14(8):673-82.
4. Locker D. The symptom iceberg in dentistry. Treatment-seeking in relation to oral and facial pain. *J Can Dent Assoc.* 1988 Apr;54(4):271-4.
5. Macfarlane TV, Kincey J, Worthington HV. The association between psychological factors and oro-facial pain: a community-based study. *European journal of pain (London, England).* 2002;6(6):427-34.
6. Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Factors associated with health care seeking behaviour for orofacial pain in the general population. *Community Dent Health.* 2003 Mar;20(1):20-6.
7. Rollman A, Visscher CM, Gorter RC, Naeije M. Care seeking for orofacial pain. *Journal of orofacial pain.* 2012;26(3):9.
8. Diatchenko L, Nackley AG, Slade GD, Fillingim RB, Maixner W. Idiopathic pain disorders--pathways of vulnerability. *Pain.* 2006 Aug;123(3):226-30.
9. Plesh O, Wolfe F, Lane N. The relationship between fibromyalgia and temporomandibular disorders: prevalence and symptom severity. *J Rheumatol.* 1996 Nov;23(11):1948-52.
10. Dworkin SF. Perspectives on the interaction of biological, psychological and social factors in TMD. *J Am Dent Assoc.* 1994 Jul;125(7):856-63.
11. Ferreira M, Machado G, Latimer J, Maher C. Factors defining care-seeking in low back pain - A meta-analysis of population based surveys. *European Journal of Pain.* [Meta-analysis]. 2010; 14:747.e1-747.e7.
12. Mortimer M, Ahlberg G. To seek or not to seek? Care-seeking behaviour among people with low-back pain. *Scand J Public Health.* 2003;31(3):194-203.

13. Campbell SM, Roland MO. Why do people consult the doctor? *Fam Pract*. 1996 Feb;13(1):75-83.
14. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995 Jul 1;311(6996):42-5.
15. Forman J, Creswell JW, Damschroder L, Kowalski CP, Krein SL. Qualitative research methods: key features and insights gained from use in infection prevention research. *Am J Infect Control*. 2008 Dec;36(10):764-71.
16. Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: review, criteria, examinations and specifications, critique. *J Craniomandib Disord*. 1992 Fall;6(4):301-55.
17. Kvale S, editor. *InterViews: An Introduction to Qualitative Research Interviewing*. Thousands Oaks: Sage; 1996.
18. Durham J, Steele JG, Wassell RW, Exley C. Living with uncertainty: temporomandibular disorders. *Journal of dental research*. 2010 Aug;89(8):827-30.
19. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl* 1965;12:436-45.
20. Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. *Am J Public Health*. 1984 Sep;74(9):979-83.
21. Jones J, Hunter D. Consensus methods for medical and health services research. *BMJ*. 1995 Aug 5;311(7001):376-80.
22. Durham J, Steele J, Moufti MA, Wassell R, Robinson P, Exley C. Temporomandibular disorder patients' journey through care. *Community Dent Oral Epidemiol*. 2011; Dec;39(6):532-41.
23. Wolf E, Birgerstam P, Nilner M, Petersson K. Nonspecific chronic orofacial pain: studying patient experiences and perspectives with a qualitative approach. *Journal of orofacial pain*. 2008 Fall;22(4):349-58.
24. Edmunds S, Brown G. Doing qualitative research in dentistry and dental education. *Eur J Dent Educ*. 2012; May;16(2):110-7.
25. Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*. 2000 Apr;85(3):317-32.

26. Gatchel RJ, Stowell AW, Wildenstein L, Riggs R, Ellis E, 3rd. Efficacy of an early intervention for patients with acute temporomandibular disorder-related pain: a one-year outcome study. *J Am Dent Assoc.* 2006 Mar;137(3):339-47.
27. Fox S. Health information is a popular pursuit online. 2011. [http://www.sahs.uth.tmc.edu/evbernstam/HI6308\\_Materials/PIP\\_Health\\_Report.pdf](http://www.sahs.uth.tmc.edu/evbernstam/HI6308_Materials/PIP_Health_Report.pdf)
28. Friction JR. Development of orofacial pain programs in dental schools. *Journal of orofacial pain.* 2002;16(3):191-7.
29. Nilner M. Curriculum guidelines for orofacial pain and temporomandibular disorders. European Academy of Craniomandibular Disorders. *Eur J Dent Educ.* 2001 Aug;5(3):136-8.
30. Lobbezoo F, van der Zaag J, Visscher CM, Naeije M. Oral kinesiology. A new postgraduate programme in the Netherlands. *J Oral Rehabil.* 2004 Mar;31(3):192-8.



## **Chapter 6**

### **Improvement in patients with a TMD-pain report. A six-month-follow-up study.**

**Annemiek Rollman, Corine M. Visscher, Ronald C. Gorter,  
Machiel Naeije**

## Abstract

Even though chronic TMD pain tends to persist in most patients, some chronic patients show improvement. It is largely unknown which factors contribute to the improvement of chronic pain. The aim of this study is to investigate which factors, from a biopsychosocial perspective, help to predict improvement in patients with a report of TMD pain. Methods: Subjects with a report of TMD pain were recruited in seven TMD-clinics. They received a baseline questionnaire which included a wide range of possible predictors for improvement. After 6 months they received a follow-up questionnaire which included a measure to determine which participants were “improved” or “not improved”. To study which predictive variables were associated with improvement, multiple regression models were built. Results: From the 129 patients that responded to the baseline questionnaire, 100 patients also filled in the follow-up questionnaire (85% female, mean age (years)  $\pm$ SD = 46.0  $\pm$ 13.8). Fifty percent of these subjects had improved at the 6-month follow-up. Pain duration was the strongest (negative) predictor for 6-month improvement ( $p=0.009$ ). Also the number of care providers ( $p=0.017$ ) and the degree of hindrance on function ( $p=0.045$ ) helped to predict improvement. Conclusions: The duration of the TMD-pain complaint, the number of care practitioners attended and the degree of hindrance on function (negatively) helped to predict 6-month improvement. No evidence is found to support the role of psychological or social factors on the improvement in patients with a report of TMD pain.

Key words: TMD pain, follow-up, improvement, biopsychosocial factors

## Introduction

Orofacial pain refers to pain in the region of the head, face and mouth. Depending on the definition used, its population prevalence ranges from 1% (current cheek pain) to 48% (current oral or facial pain) [1]. The most common type of acute orofacial pain is toothache [2], whereas chronic orofacial pain is mostly associated with a temporomandibular disorder (TMD) [3]. Chronic TMD pain seldom appears as an isolated complaint. More than half of the patients presenting at a TMD clinic also reported pain in the neck [4], and also widespread pain is commonly reported by these patients [4, 5]. In addition, TMD patients often present with psychological complaints like depression and anxiety [6, 7].

Even though chronic pain tends to persist in most patients, some chronic pain patients show improvement. For example, in a group of chronic musculoskeletal pain patients (including patients with neck pain or back pain) about one-third improved over an 8-10 year period [8]. Comparable rates of long-term improvement have been reported in chronic TMD patients [9]. However, it is largely unknown which factors contribute to the improvement of chronic pain. To name a few considerations: is the way patients cope with their pain an important factor, or are psychological factors involved? In a systematic review on back pain patients, depression, psychological distress, passive coping

strategies and fear-avoidance beliefs were inconsistently found to be associated with poor outcome (on sick leave and functional improvement), whereas most social and socio-occupational factors were not predictive for improvement [10]. For TMD pain, only a few prospective studies on predictors for improvement have been published, with inconsistent results [9, 11 - 14]. For example, one study on acute TMD patients reported that baseline pain intensity and a diagnosis of myofascial pain were predictive for poor outcome at 6-month follow-up [13]. In another study, where a group of chronic TMD patients were followed over a 5-year period, these predictors were not confirmed. Instead, baseline pain frequency, somatization, widespread pain and a diagnosis of arthralgia were found to be associated with poor outcome [9].

As for back pain, where the Cochrane Back Review Group stated that highlighting factors that influence the improvement of low back pain is a major challenge to improve prognosis [15], prospective studies on the improvement of TMD pain are warranted. Therefore, the aim of this study is to investigate which factors, from a biopsychosocial perspective, help to predict improvement in patients with a TMD-pain report.

## Material and Methods

### Study population

This study is part of a larger project on care seeking behavior in patients with a report of TMD pain, and details about the study have been described extensively elsewhere [16]. In short, inclusion criteria for adults to be eligible for participation were a referral for a TMD-pain complaint to one of 7 participating centers for Temporomandibular Disorders (located in Amsterdam [two centers], Alkmaar, Arnhem, Breda, Den Haag, and Zwolle - all in The Netherlands), a self-report of OFP within the last month; and a good understanding of the Dutch language. To exclude patients with dental pain or with rare causes of orofacial pain (like neuralgias), exclusion criteria were: any report of toothache, burning sensations in the orofacial region, shooting pain that is provoked by touch, a diagnosis of a systemic disease, or cancer. This enlarges the likeliness that the pain complaint of most (if not all) of the participants was related to a temporomandibular disorder. At baseline, all patients signed an informed consent form in which they stated that they allowed the principal investigator to contact them for a follow-up measurement.

One-hundred-twenty-nine patients with a report of TMD pain who met the inclusion criteria filled in the baseline questionnaire [16]. Six months later, they were contacted by mail to fill in a short follow-up questionnaire. When participants did not respond within 3 weeks, a reminder was sent. If necessary, a second reminder was given after 6 weeks. Participants who did not reply to any of the reminders were contacted by phone in order to gather information regarding the main outcome measure (improved/not improved), and whether they had received treatment in the past 6 months. In total, 100 subjects responded to the follow-up questionnaire (responders) and 29 did not (non-responders).

### Baseline questionnaire

The baseline questionnaire consisted of a wide variety of variables that could (help) predict which patients are likely to improve from their TMD-pain complaints within the upcoming 6 months. All variables were measured by use of standardized self-report scales. Where available, previously validated measures were chosen.

*Pain duration:* classified as 0-3 months, 3-6 months, 6-12 months, 1-3 years, 3-10 years, or >10 years.

*Pain intensity:* measured by the 'Characteristic Pain Intensity' (CPI) which is part of the graded chronic pain scale [17, 18]. For the CPI, the 0 to 10 ratings of questions regarding 'current pain', 'worst pain in the past 6 months', and 'average pain in the past 6 months', are averaged and multiplied by 10 (range: 0-100; higher scores denote more pain).



*Pain-related disability:* rated by the 'Disability Score' (DS) which is part of the graded chronic pain scale [17, 18]. For the DS, 0 to 10 ratings of interferences of the TMD-pain complaints with 'daily activities', 'social activities', and 'work/housework in the past 6 months' are averaged and multiplied by 10 (0-100; higher scores denote more disability).

*Hindrance on Function:* measured by the 'Patient Specific Approach' (PSA) [19]. For the PSA, participants report the activity they regard most important and difficult to perform because of their TMD-pain complaints. The amount of hindrance experienced during this activity is then measured on a 100-mm Visual Analogue Scale (0-100; higher scores denote more hindrance on function).

*Widespread pain:* sites that were painful within the past 6 months were marked on the body drawing of the McGill Pain Questionnaire [20, 21]. The number of painful body sites outside the orofacial region were counted according to the method proposed by Lobbezoo et al. [22]; neck, shoulders, arms, chest, abdomen, back, and legs (0-7; higher scores denote more widespread pain).

*Number of care practitioners:* the total number of healthcare practitioners the participant previously visited for their pain complaint.

*Use of pain killers:* current use of pain killers for their pain complaint. (yes/no).

*Fear of movement:* measured by a 4-point score (ranging from 'strongly disagree' (1) to 'strongly agree' (4)) on the statement "I'm afraid that I might injure myself if I move my jaw". This item was derived from the Tampa Scale for Kinesiophobia for Temporomandibular Disorders (1-4; higher scores denote more fear of movement) [23]. To control the length of the questionnaire, only 1 item of the original TSK-TMD was included. This item was chosen because of its simple and clear formulation, and because its scores relate well with the score of the activity avoidance subscale of the TSK-TMD [23].

*Coping strategies:* catastrophizing (1-6; higher scores denote more catastrophical thoughts about pain), pain coping (1-6; higher scores denote the use of more different strategies to cope with pain), internal pain control (1-6; higher scores denote more positive expectancies about personal control over pain), and external pain control (1-6; higher scores denote more positive expectancies about control over pain by others) were measured by the Pain Coping and Cognition List (PCCL) [24].

*Psychological distress:* depression, somatization and anxiety were measured by the Dutch version of the Symptom Check List 90 (SCL-90 DV) [25, 26]. In this checklist, depression represents symptoms of low mood and aversion to activity, (range: 16-76; higher scores denote more depression within the last month), somatization represents bodily symptoms, such as faintness and stomach upset, associated with a general feeling of physical complaints (range: 12-60; higher scores denote more somatization within the last month) and anxiety represents symptoms of nervousness, tension, panic and

restlessness) (range: 10-50; higher scores denote more anxiety within the last month). The depression, somatisation and anxiety scores were then classified as “normal”, “moderate” or “severe” using the thresholds for the Dutch population [27]: very low-above average = “normal”, high = “moderate” and very high = “severe”.

*Dental anxiety:* measured by the Dental Anxiety Scale (DAS) [28, 29]. This scale measures fear of a visit to the dentist and anxiety over dental procedures (4-20; higher scores denote more anxiousness).

*Level of education:* classified as no education, low (primary school), middle (junior vocational education/secondary vocational education), or high (vocational colleges/university) [30].

*Employment:* current employment (yes/no).

*Household situation:* currently living alone (yes/no).

Besides information on the above-described putative predictors for improvement, also information regarding age (in years), gender, and city of recruitment was noted.

#### Six-month follow-up questionnaire

*Improved/not improved.* At the follow-up measurement, improvement was measured based on the following question: “Did the pain in your face that you reported half a year ago...”: “completely disappear”, “largely decrease”, “slightly decrease”, “remain the same”, “increase slightly” or “increase a lot”. In line with previous studies on low-back pain [31-33], patients who reported that their TMD-pain complaints had “completely disappeared” or “largely decreased” were classified as “improved”, and the other patients were classified as “not-improved”.

*Treatment:* Participants were asked to indicate whether or not they were treated for their pain complaint in the past 6 months. The choice of treatment (e.g. dentist, physiotherapy or psychologist), nor the implementation of that treatment was standardized. Participants who reported that they had not seen a specialist were categorized as “not treated”, all others were considered to have undergone “treatment”.

The study was approved by the medical ethical committee of the VU University of Amsterdam (file number 2004/166).

## Data analyses

T-tests and  $\chi^2$ -tests were used to analyze whether any baseline differences were present between responders (i.e. the participants who filled in the follow-up questionnaire; N=100) and non-responders (N=29) of the follow-up measurement.

A multiple logistic regression model was built to evaluate which baseline variables best predict improvement of the TMD-pain complaints at the 6-month follow-up. First, single regression analyses were performed to determine which variables univariately predicted improvement. For ordinal variables, linearity of their effect on improvement was checked by analysis of dummy variables. When the regression coefficients of the dummy variables did consistently increase (or decrease), linearity was considered present. In case of a non-linear association, either a log-transformation or dichotomization of the variable was conducted (depending on the variable).

Predictors that showed at least a moderate association with 'improvement' (i.e., p-value  $\leq 0.10$ ) were entered in the multiple regression analysis. Then, the variable with the weakest association with 'improvement' was removed from the multiple regression model. This was repeated in a backward stepwise manner, until all variables that were retained in the model showed a p-value  $\leq 0.05$ . For the variables that were retained in the multiple regression model, it was checked whether any significant interactions were present between these variables. As a final step, age, gender, place of recruitment and treatment in the past 6 months were entered in the multiple regression model to determine whether there were any confounding effects. Confounding was considered present when adding one of these variables to the multiple regression model would change the regression coefficient of any of the predictors by more than 10% [16].

The Statistical Package for Social Sciences (SPSS 17.0) was used to analyze the data and  $\alpha < 0.05$ .

## Results

Seventy-eight participants returned the 6-month follow-up questionnaire. Information regarding the main outcome measure (improved/not improved) of 22 additional participants could be collected by the phone call. This resulted in a total follow-up study sample consisting of 100 participants (Response Rate = 78%). Persons who did not respond to the follow-up questionnaire (N=29, 76% female, mean age (years)  $\pm$ SD = 43.4  $\pm$ 13.3) did not differ from the responders (85% female, mean age (years)  $\pm$ SD = 46.0  $\pm$ 13.8) with respect to any of the putative predictive variables measured on baseline ( $t = -1.79$ -0.18,  $p = 0.34$ -0.55;  $\chi^2 = 4.01$ -2.17,  $p = 0.07$ -0.86).

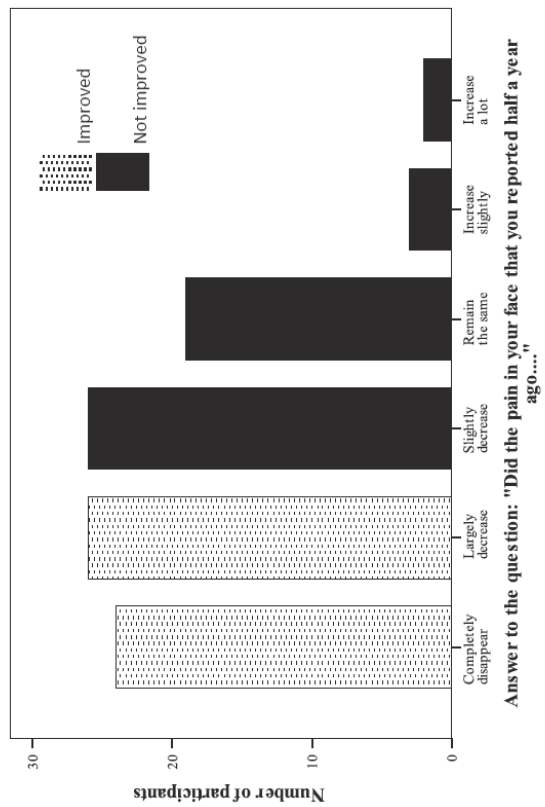
At the 6-month follow-up measurement, 50 of the 100 patients (50%) had improved on their TMD-pain complaints (i.e., their pain complaint completely disappeared or largely decreased, see Fig. 1). In Table 1 the descriptives of the putative predictors for

improvement are presented for the group of participants that had improved, and for the group that had not improved.

#### Baseline predictors for 6-month improvement of orofacial pain.

The inspection of the regression coefficients of the dummy variables for pain duration showed that the effect of pain duration on improvement TMD-pain complaints was not linear. Since a log-transformation of pain duration did not result in a linear association with improvement, the variable pain duration was dichotomized into a group of patients with 'short-pain duration' and a group of patients with 'long-pain duration'. Based on the distribution of pain duration in the study sample (Table 1), the cut-off to separate short-pain duration from long-pain duration was set at 1 year ( $\leq 1$  year, N=43;  $> 1$  year, N=57).

In Table 2 the results of the single logistic regression analyses (with pain duration dichotomized) and the subsequent multiple logistic regression analysis are presented. Pain duration was, by far, the strongest predictor for 6-month improvement ( $p=0.009$ ): patients with pain complaints for more than 1 year were four times less likely (OR: 0.25) to improve than patients with a shorter duration of pain. In addition, also the number of care providers ( $p=0.017$ ) and the degree of hindrance on function ( $p=0.045$ ) helped to predict improvement: the more care practitioners attended, and the more the oral function was hindered by the pain complaint, the poorer the prognosis. There were no interaction effects ( $p=0.07-0.73$ ) and there was no confounding by age, gender, or treatment (change in regression coefficients (b)=0.0-10.0%). Confounding by city of recruitment could only be determined when Zwolle was omitted from the analysis (because only 1 participant from that city was included in the follow-up study), and also resulted in no confounding effects (change in regression coefficients (b)=0.0- 9.1%) on the three predictors for improvement of TMD-pain complaints.



Answer to the question: "Did the pain in your face that you reported half a year ago...."

Fig. 1. Descriptives of the main outcome measure.

Table 1: Descriptives of the putative predictive variables and confounders for 6-month improvement of orofacial pain

Predictive variables		Improved (N=50)	Not Improved (N=50)
Pain duration (1-6) (n=100)			
	0 months - 3 months	16%	2%
	≥ 3 months < 6 months	30%	10%
	≥6 months <1 year	14%	14%
	≥1 year < 3 years	26%	24%
	≥3 years < 10years	10%	20%
	≥10 years	4%	30%
Pain intensity (0-100) (n=98)		52.4 (19.3)	54.8 (18.6)
Pain-related disability (0-100) (n=98)		24.3 (28.4)	33.9 (29.1)
Hindrance on function (0-100) (n= 84)		36.9 (29.1)	44.7 (28.7)
Widespread Pain (1-7) (n=98)		2.0 (2.0-3.5)	2.0 (1.0-3.0)
Number of care practitioners for TMD-pain complaints (n=97)		0.5 (1.3-2.2)	1.0 (0-2.5)
Use of pain killers (yes): (n=98)		50%	52%
Fear of movement (1-4) (n=100)		1.0 (1.0-3.0)	1.5 (1.0-3.0)
Catastrophizing (1-6) (n=97)		1.7 (1.3-2.3)	2.0 (1.3-2.0)
Pain Coping (1-6) (n=97)		3.2 (2.5-3.8)	2.8 (2.0-3.6)
Internal pain control (1-6) (n=97)		3.4 (2.6-4.3)	2.8 (2.2-3.9)
External pain control (1-6) (n=97)		2.8 (2.0-3.3)	2.6 (1.8-3.3)
Depression (n=99)			
	Normal	80%	72%
	Moderate	11%	20%
	Severe	9%	8%
Somatic complaints (n=99)			
	Normal	68%	60%
	Moderate	20%	22%
	Severe	10%	8%
Anxiety (n=99)			
	Normal	82%	70%
	Moderate	12%	22%
	Severe	6%	8%
Dental Anxiety Scale (4-20) (n=81)		7.6 (2.6)	8.1 (3.9)
Level of education (n=92)			
	No	0%	7%
	Low	0%	2%
	Middle	61%	57%
	High	39%	34%

<b>Predictive variables</b>	<b>Improved (N=50)</b>	<b>Not Improved (N=50)</b>
Employment (yes) (n=97)	65%	71%
Household Situation (living alone) (n=98)	27%	23%
<b>Confounders</b>		
Treatment (N=100) (yes)	82%	66%
Age (years) (n=100)	47.1 (13.3)	44.8 (14.2)
Gender (female) (n=100)	82%	88%
City of recruitment		
Amsterdam	80%	68%
Alkmaar	8%	8%
Arnhem	2%	6%
Breda	2%	4%
Den Haag	6%	14%
Zwolle	0%	0%

*Note.* Continuous variables are presented as mean values (and standard deviation); for ordinal data the median (and 25th-75th percentiles) are given; categorical variables are presented as percentages. If N<100, scores were not filled in (correctly) and therefore missing. The following items missed more than 10 scores: Hindrance on function (13 missing values; 3 outliers, see discussion); DAS: was the last item of the survey, which might have led to a lack of attention to this scale by some subjects.

**Table 2.** Predictive variables for 6-month improvement of TMD-pain complaints

Predictive variables	Single regression			Step 1 Multiple regression ( <i>n</i> = 78)			Step 2 Multiple regression ( <i>n</i> = 79)			Step 3 Multiple regression ( <i>n</i> = 81)		
	<i>N</i>	<i>b</i>	<i>P</i>	OR (95%-CI)	<i>b</i>	<i>P</i>	OR (95%-CI)	<i>b</i>	<i>P</i>	OR (95%-CI)	<i>b</i>	<i>P</i>
Pain duration (0–1)	100	–1.45	0.001	0.51 (0.10–0.55)	–0.69	0.001	0.50 (0.34–0.76)	–1.23	0.026	0.29 (0.10–0.86)	–1.39	0.009
Number of care practitioners for	97	–0.49	0.007	0.61 (0.43–0.88)	–0.42	0.069	0.66 (0.42–1.03)	–0.46	0.048	0.63 (0.41–0.98)	–0.52	0.017
TMD-pain complaints												
Hindrance on function (0–100)	84	–0.02	0.040	0.98 (0.97–0.99)	–0.02	0.072	0.98 (0.96–1.00)	–0.02	0.048	0.98 (0.96–1.00)	–0.02	0.045
Pain coping (1–6)	97	0.38	0.077	1.46 (0.96–2.21)	0.25	0.347	1.28 (0.76–2.15)	0.27	0.295	1.32 (0.79–2.20)		
Pain-related disability (0–100)	97	–0.01	0.055	0.99 (0.97–1.00)	–0.01	0.651	0.995 (0.98–1.02)					

*b*, regression coefficient; OR, odds ratio; CI, confidence interval. The number of patients included in the various steps of the multiple regression analysis varied slightly as related to some missing values on the predictive variables.



## Discussion

The results of this study show that pain duration is the strongest, negative predictor for 6-month improvement of TMD-pain complaints. Additional variables that contribute to the prediction of improvement are the number of care practitioners previously attended for the pain complaints and the amount of hindrance on the specific oral function that was selected by the patient as most important and hampered by the pain.

There are some strengths and weaknesses in this study. Strengths of the study include the high response rate (78%), the lack of baseline differences between responders and non-responders, and the wide range of putative predictors (covering physical, psychological and social aspects) studied. Weaknesses of the study include the fact that treatment was not controlled for, the relatively small sample size, and the number of missing values for some variables. Since this study was not designed as a randomized clinical trial, treatment type and implementation of that treatment were not controlled for. Earlier studies have however consistently shown that even though patients benefit from conservative treatments (like oral appliance or home exercises) for TMD pain, it is less important what type of treatment is provided [34, 35]. Bearing this in mind, the decision to check for possible confounding effects of treatment (yes/no) on the results presented in this paper seems sufficient. This analysis of confounding showed that irrespective of whether a patient was treated or not, patients with less pain duration, who had attended less care practitioners and who reported less hindrance on function are more likely to show improvement within the upcoming 6 months.

The sample size of the follow-up study was 100 participants. In prospective studies, it is difficult to predict the number of 'cases' (in this study, the patients who showed improvement at the 6-month follow-up) and 'controls' (patients who did not improve). Coincidentally, the number of cases and controls was equally distributed (for both groups N=50) which allowed for building a multiple regression model for improvement of TMD-like pain with up to 5 predictors, applying the rule of thumb to the multiple logistic regression analysis: '10 cases of data for each predictor in the model' [36]. Since only 5 predictors were selected from the single regression analysis, and only 3 predictors were retained in the final regression model, the sample size was adequate for the regression analysis.

For one of the predictors for improvement of TMD-pain complaints (i.e., hindrance on function as measured with the patient specific approach) 16 missing values were present. Thirteen patients did not report a specific activity which was difficult to perform because of their TMD-pain complaints, and therefore no VAS scores were available. In addition, 3 patients rated their activity (i.e. yawning, opening the mouth, and doing sports) as impossible to perform because of their TMD-pain complaints (VAS score=100). However, the outcomes of the clinical examination (including maximal mouth opening, data not presented) of these patients contradicted the scores of the patient specific approach (PSA), suggesting that these patients probably did not understand the intent of the patient-specific approach. Therefore, their scores were skipped from the analysis.

For future studies, to prevent missing values on this measure, we recommend to provide verbal instructions on the use of the patient specific approach at the initial visit [19].

That those with short term TMD-like pain are more likely to improve on follow-up, while those with more chronic TMD-like pain do not improve, seems self-evident proof that chronic means tends to persist [9, 37]. Interestingly, also the number of care practitioners previously visited for the TMD-pain complaints negatively contributed to the chance of improvement at the 6-month follow-up. This confirms an earlier suggestion of Rammelsberg et al., who reported that about half of the patients with persistent TMD-pain still received treatment [9]. This can be interpreted as the result of a negative coping style: even though previous care providers were not successful in treating the patient, the patient still believes that someone else will be able to help. However, this interpretation is contradicted by the finding that the coping strategy 'external pain control' (which measures the degree of positive expectancies about control over pain by others) was not related to improvement of TMD-pain complaints. So possibly, the number of care practitioners previously visited for the TMD-pain complaints is more an indication of the complexity of the complaint (e.g., a complicated diagnosis), or, in some cases, a reflection of the lack of knowledge in the field of TMD pain.

The third predictor for improvement of TMD-pain complaints after a 6-month follow-up period was hindrance on function as measured with the patient specific approach (PSA). The PSA showed a much stronger association with improvement than the pain-related disability scale (see Table 2). Although both scales rate the degree of functional limitation, the PSA is tailored to the individual complaint, whereas the pain-related disability scale is more generic. Generic measures have been suggested to be less responsive to change and may also be less predictive for improvement of pain [38]. In a recent review on outcome measures for chronic low back pain, the use of specific measures that rate what is most important to the individual patient is strongly recommended [39]. Therefore, we suggest the use of the PSA in future research on TMD pain.

Even though this study revealed some predictors for the improvement of TMD-pain complaints, perhaps an even more interesting finding relates to the fact that most predictors included in the study are not associated with improvement. In such situations, the possibility of a too small sample size to detect associations should be considered. Since others have reported that baseline pain intensity, widespread pain and catastrophizing helped to predict outcome in TMD patients, the current results on these variables should be interpreted with caution. The finding that no association is found with depression and disability is however a confirmation of earlier studies [9, 11-14]. In the field of low back pain and neck pain, much more studies on predictors for improvement have been published [10, 40, 41]. However, also in that area, only few predictors (e.g., depression, history of previous attacks, passive coping strategies and fear-avoidance beliefs) were inconsistently reported to predict poor outcome, while other factors (e.g., anxiety, social factors and occupational factors) were not. Perhaps, the lack of reproducible predictors for poor outcome in musculoskeletal pain patients

merely illustrates that the assumption that certain baseline characteristics are related to improvement of musculoskeletal pain is an oversimplification of the truth. Associations between baseline characteristics and long-term outcomes probably are not simple cause-and-effect relationships. Instead, various patient characteristics probably act together, and perhaps even unknown factors (like genetics) may play a role in the perpetuation of musculoskeletal pain complaints.

The aspects found in this study only partly explain why some patients improve, while others do not. This suggests that other yet unknown aspects must be of influence, which is illustrated by the story of one of the participants of this study: a lady of 39 years old presented TMD-pain complaints which already lasted for more than 10 years. She had never attended a care practitioner for this complaint before, because she was not (made) aware of the possibility of treatment for her complaints. She was diagnosed with myofascial TMD pain and subsequently treated with physiotherapy. At the 6-month follow-up measurement she reported that her pain had “largely decreased”. This example not only shows that in patients with a long history of complaints, but without (extensive) prior treatment, prognosis for improvement may still be favorable, but also that referral to an appropriate care practitioner is sometimes hampered by lack of knowledge of both first-care providers and patients. To better understand the interdependence between factors that are related to the improvement, or even to detect new factors that are not commonly included in quantitative study designs, qualitative studies may be a suitable approach. For example, semi-structured interviews with patients who show poor outcome and patients with good outcome may provide new insights in the mechanisms involved in treatment success.

## Conclusions

Within the limits of this study, the duration of the TMD-pain complaints, the number of care practitioners attended and the degree of hindrance on function (negatively) helped to predict 6-month improvement. No evidence is found to support the role of psychological or social factors on the improvement in patients with a report of TMD pain.

## **Acknowledgements**

We would like to thank the collaborating TMD clinics for their help in the recruitment and follow-up of OFP patients: Amphia Ziekenhuis Breda, Haga Ziekenhuis Den Haag, Isala Klinieken Zwolle, Medisch Centrum Alkmaar, Stichting Bijzondere Tandheelkunde Amsterdam, and Ziekenhuis Rijnstate Arnhem. Especially, we like to thank all patients for their participation in the research. This study was supported by the Institute for Dental Sciences in the Netherlands (IOT).

## References

- [1] Macfarlane TV, Glenny AM, Worthington HV. Systematic review of population-based epidemiological studies of oro-facial pain. *J Dent*. 2001;29: 451-67.
- [2] Lipton JA, Ship JA, Larach-Robinson D. Estimated prevalence and distribution of reported orofacial pain in the United States. *J Am Dent Assoc*. 1993;124: 115-21.
- [3] Fillingim RB, Wallace MR, Herbstman DM, Ribeiro-Dasilva M, Staud R. Genetic contributions to pain: a review of findings in humans. *Oral Dis*. 2008;14: 673-82.
- [4] Visscher CM, Lobbezoo F, de Boer W, van der Meulen M, Naeije M. Psychological distress in chronic craniomandibular and cervical spinal pain patients. *Eur J Oral Sci*. 2001;109: 165-71.
- [5] Turp JC, Kowalski CJ, O'Leary N, Stohler CS. Pain maps from facial pain patients indicate a broad pain geography. *J Dent Res*. 1998;77: 1465-72.
- [6] Von Korff M, Simon G. The relationship between pain and depression. *Br J Psychiatry Suppl*. 1996: 101-8.
- [7] Visscher CM, Lobbezoo F, de Boer W, van der Zaag J, Naeije M. Prevalence of cervical spinal pain in craniomandibular pain patients. *Eur J Oral Sci*. 2001;109: 76-80.
- [8] Magni G, Marchetti M, Moreschi C, Merskey H, Luchini SR. Chronic musculoskeletal pain and depressive symptoms in the National Health and Nutrition Examination. I. Epidemiologic follow-up study. *Pain*. 1993;53: 163-8.
- [9] Rammelsberg P, LeResche L, Dworkin S, Mancl L. Longitudinal outcome of temporomandibular disorders: a 5-year epidemiologic study of muscle disorders defined by research diagnostic criteria for temporomandibular disorders. *J Orofac Pain*. 2003;17: 9-20.
- [10] Ramond A, Bouton C, Richard I, Roquelaure Y, Baufreton C, Legrand E, et al. Psychosocial risk factors for chronic low back pain in primary care—a systematic review. *Fam Pract*. 2010;28: 12-21.
- [11] Ohrbach R, Dworkin SF. Five-year outcomes in TMD: relationship of changes in pain to changes in physical and psychological variables. *Pain*. 1998;74: 315-26.
- [12] van Selms MK, Lobbezoo F, Naeije M. Time courses of myofascial temporomandibular disorder complaints during a 12-month follow-up period. *J Orofac Pain*. 2009;23: 345-52.
- [13] Epker J, Gatchel RJ, Ellis E, 3rd. A model for predicting chronic TMD: practical application in clinical settings. *J Am Dent Assoc*. 1999;130: 1470-5.

- [14] Velly AM, Look JO, Carlson C, Lenton PA, Kang W, Holcroft CA, et al. The effect of catastrophizing and depression on chronic pain--a prospective cohort study of temporomandibular muscle and joint pain disorders. *Pain*. Oct;152(10):2377-83.
- [15] Bouter LM, Pennick V, Bombardier C. Cochrane back review group. *Spine* 2003;28: 1215-8.
- [16] Rollman AV, CM Gorter, RC Naeije, M. Care seeking for orofacial pain *Journal of Orofacial Pain*. in press.
- [17] Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: review, criteria, examinations and specifications, critique. *J Craniomandib Disord*. 1992;6: 301-55.
- [18] Lobbezoo F, van Selms MK, John MT, Huggins K, Ohrbach R, Visscher CM, et al. Use of the Research Diagnostic Criteria for Temporomandibular Disorders for multinational research: translation efforts and reliability assessments in The Netherlands. *J Orofac Pain*. 2005;19: 301-8.
- [19] Rollman A, Naeije M, Visscher CM. The reproducibility and responsiveness of a patient-specific approach: a new instrument in evaluation of treatment of temporomandibular disorders. *J Orofac Pain*. 2010;24: 101-5.
- [20] Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. *Pain*. 1975;1: 277-99.
- [21] van der Kloot WA, Vertommen H. De MPQ-DLV, een standaard Nederlandstalige versie van de McGill Pain Questionnaire: Achtergronden en handleiding. Lisse: Swets & Zeitlinger; 1989.
- [22] Lobbezoo F, Visscher CM, Naeije M. Impaired health status, sleep disorders, and pain in the craniomandibular and cervical spinal regions. *Eur J Pain*. 2004;8: 23-30.
- [23] Visscher CM, Ohrbach R, van Wijk AJ, Wilkosz M, Naeije M. The Tampa Scale for Kinesiophobia for Temporomandibular Disorders (TSK-TMD). *Pain*. 2010;150: 492-500.
- [24] Stomp-van den Berg SGM, Vlaeyen JWS, ter Kuile MM, Spinhoven P, van Breukelen G, Kole-Snijders AMJ. Pijn Coping en Cognitie Lijst. <http://www.pijn.com/medici/index5.htm>. 2001.
- [25] Derogatis LR, Lipman RS, Covi L. SCL-90: an outpatient psychiatric rating scale--preliminary report. *Psychopharmacol Bull*. 1973;9: 13-28.
- [26] Arrindell W, Ettema J. Handleiding bij een multidisciplinaire psychopathologie-indicator. Lisse: Swets & Zeitlinger 1986.

- [27] Arrindell WAE, J H M SCL-90; Handleiding bij een multidimensionele psychopathologie-indicator. Lisse, The Netherlands: Swets Test Publishers 2003.
- [28] Corah NL. Development of a dental anxiety scale. *J Dent Res*. 1969;48: 596.
- [29] Schuurs AH, Hoogstraten J. Appraisal of dental anxiety and fear questionnaires: a review. *Community Dent Oral Epidemiol*. 1993;21: 329-39.
- [30] Wijnhoven HA, de Vet HC, Picavet HS. Sex differences in consequences of musculoskeletal pain. *Spine*. 2007;32: 1360-7.
- [31] van der Roer N, Ostelo RW, Bekkering GE, van Tulder MW, de Vet HC. Minimal clinically important change for pain intensity, functional status, and general health status in patients with nonspecific low back pain. *Spine (Phila Pa 1976)*. 2006;31: 578-82.
- [32] Beurskens AJ, de Vet HC, Koke AJ. Responsiveness of functional status in low back pain: a comparison of different instruments. *Pain*. 1996;65: 71-6.
- [33] Ostelo RW, de Vet HC, Knol DL, van den Brandt PA. 24-item Roland-Morris Disability Questionnaire was preferred out of six functional status questionnaires for post-lumbar disc surgery. *J Clin Epidemiol*. 2004;57: 268-76.
- [34] Feine JS, Widmer CG, Lund JP. Physical therapy: a critique. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod*. 1997;83: 123-7.
- [35] Dao TT, Lavigne GJ, Charbonneau A, Feine JS, Lund JP. The efficacy of oral splints in the treatment of myofascial pain of the jaw muscles: a controlled clinical trial. *Pain*. 1994;56: 85-94.
- [36] Field A. *Discovering Statistics Using SPSS*. In: D Wright, ed. *ISM Introducing statistical methods*. 2 ed. London: SAGE Publications Ltd 2005.
- [37] Swinkels IC, Wimmers RH, Groenewegen PP, van den Bosch WJ, Dekker J, van den Ende CH. What factors explain the number of physical therapy treatment sessions in patients referred with low back pain; a multilevel analysis. *BMC Health Serv Res*. 2005;5: 74.
- [38] Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. *J Chronic Dis*. 1987;40: 171-8.
- [39] Chapman JR, Norvell DC, Hermsmeyer JT, Bransford RJ, DeVine J, McGirt MJ, et al. Evaluating common outcomes for measuring treatment success for chronic low back pain. *Spine (Phila Pa 1976)*. 2011;36: S54-68.

[40] Pincus T, Burton AK, Vogel S, Field AP. A systematic review of psychological factors as predictors of chronicity/disability in prospective cohorts of low back pain. *Spine*. 2002;27: E109-20.

[41] Borghouts JA, Koes BW, Bouter LM. The clinical course and prognostic factors of non-specific neck pain: a systematic review. *Pain*. 1998;77: 1-13.



## **Chapter 7**

### **General Discussion**

As for other musculoskeletal disorders, the prognosis for the majority of Temporomandibular disorders (TMD)- pain is favorable[1] [2] [3]. About half of the people with TMD-pain complaints seeks care for their complaints [4]. Epidemiological studies show that also non-care seekers often improve from their complaints naturally. For those who do seek care, common treatments are counseling, physiotherapy and oral appliances. Of these patients about 75-85% benefit from these treatments [5]. However for some patients treatment success becomes difficult to achieve, and pain complaints last. Some of these patients continue their search for treatment. Especially in those, pain may not only impair physical function, but may also result in mental and emotional difficulties, and a diminished quality of life [6, 7]. It is commonly accepted that biopsychosocial factors play a role in TMD pain. However, it is a challenge to find factors involved in treatment success in those patients that already have complaints for long periods of time and that have underwent previous treatment. To improve patient care, particularly for those with long lasting pain complaints, much can be gained by further understanding the factors that influence the development of pain. Therefore, the aim of this thesis was to improve the understanding of the role of biopsychosocial factors in the development TMD-pain complaints and care seeking behavior.

## In perspective

Chronic pain is usually defined by an interval of time since onset; the two most commonly used markers being 3 months and 6 months since onset [8], though some have placed the transition from acute to chronic pain at 12 months [9]. It has been proposed that chronic pain should not be defined merely by the duration of pain, but needs a multidimensional view that accounts for pain characteristics, psychological and behavioral aspects [5] [10]. Such a view would allow to recognize patients that are at risk to develop long lasting complaints at an early stage. By identifying aspects that play a role in future outcome, risks to develop poor outcome can be reduced [10].

The biopsychosocial model is a widely accepted multidimensional approach that posits that biological, psychological, and social factors, all play a significant role in the context of disease or illness [11] [12]. At the core of the biopsychosocial model is the assumption of an on-going sensation that is nociceptive in nature or which is perceived by the sufferer as being painful. The patient's cognitions, i.e. what they think and understand about this sensation, will influence their emotional responses [13]. In line with this approach, to explain why some patients recover from pain, while in others pain complaints persist, nowadays, the so-called fear-avoidance model is widely used [14]. It suggests that a minority of people respond to pain by avoiding physical activities, which may lead to a reduction of social activities and at the same time an increase of all kinds of psychological symptoms like depression, somatization and anxiety, resulting in long periods of pain [14]. In this fear-avoidance model, catastrophizing is an important precursor of chronic pain.

In our clinical studies, the biopsychosocial model was used as framework to look at the development of TMD-pain complaints and subsequent care seeking behavior. A questionnaire survey was conducted among a sample of participants with TMD pain. The questionnaire aimed to cover a wide range of potentially important biopsychosocial factors. Many instruments were available to implement in the questionnaire: the so-called 'Characteristic Pain Intensity' (CPI) [15] was used to measure pain intensity, the Symptom Check List 90 (SCL-90) [16] was used to measure depression and somatization, and coping strategies like catastrophizing were measured by the Pain Coping and Cognition List (PCCL) [17]. Next to these commonly used variables, also a recently introduced instrument to measure fear of movement for TMD (part of the fear-avoidance model) was incorporated [18]. For most factors that were considered important, measures could be adapted to apply in TMD-pain patients, others were not readily available and needed to be developed. Among these were the so-called 'Patient-Specific Approach' (PSA) measure, and a measure for social support in pain patients. The patient-specific approach measure is an instrument that is widely used in patients with other musculoskeletal complaints, like low-back pain or neck pain [19] [20]. It rates the amount of hindrance patients perceive while performing the activity that is most important to them and is hindered because of their jaw complaints. The 'Social support and Pain Questionnaire' (SPQ) is a short questionnaire that measures the satisfaction with social support related to pain. In **Chapters 2 and 3**, the development of the Patient Specific Approach measure (PSA) and the 'social support and pain questionnaire' (SPQ) is described. Both instruments were found to have good clinometric properties and were subsequently incorporated in the questionnaire.

In the questionnaire survey, biopsychosocial characteristics of those who did seek care for their TMD-pain complaints (care seekers), were compared with those who did not (non-care seekers) (**Chapter 4**). Additionally, the group of care seekers was further studied with respect to the number of care practitioners they had attended for their TMD complaints (**Chapter 4**). Moreover, in **Chapter 5**, to further investigate differences between care seekers and non-care seekers, in-depth interviews were performed. The results showed that, independent from the intensity of the pain complaint, care seekers were more alarmed by their complaints than non-care seekers. This was expressed in higher levels of fear of movement (**Chapter 4**) and more catastrophic thoughts (**Chapter 5**) among the care seekers as compared to the non-care seekers. Moreover, within the subsample of care seekers, also the continuous search for help (as expressed by the number of healthcare practitioners they had visited) was mainly related to the level of catastrophizing thoughts (**Chapter 4**), and, surprisingly, not influenced by the pain intensity. Finally, it was investigated whether biopsychosocial factors also influence the rehabilitation of TMD-pain patients in a 6-month follow-up study (**Chapter 6**). This follow-up study showed that independent from pain duration, patients who had visited many healthcare practitioners and who showed higher levels of hindrance in function (PSA), had a higher risk of unsuccessful treatment outcome (**Chapter 6**).

A notable finding of the studies was that despite the fact that many biopsychosocial variables were taken into account, only few factors were found to be predictive for care seeking (**Chapters 4 and 5**) and six-month improvement (**Chapter 6**). A possible explanation for this finding is that, even though many biopsychosocial variables are considered to influence care seeking behavior and recovery, their individual contributions are probably small. The interaction between the various biopsychosocial variables further complicates the search for evidence for the individual contribution of specific factors. Also in other longitudinal studies to the persistence of pain, only few predictors (e.g., depression, history of previous attacks, passive coping strategies and fear-avoidance beliefs) were inconsistently reported to predict poor treatment outcome [21-24].

Analogue to our findings in the comparison between care seekers and non-care seekers, in the follow-up study it was hypothesized that especially the variables that are related to the fear-avoidance model would predict six-month improvement. To our surprise, however, we found no associations between improvement and fear of either movement nor catastrophizing (**Chapter 6**). The fear-avoidance model was developed to explain the transition from acute(< 6 months) to chronic pain (> 6 months) [25]. Most of the patients in our study had pain complaints for more than 6 months. Apparently, the proposed mechanism to explain the transition from acute to chronic pain from the fear-avoidance model cannot be adopted to understand the underlying mechanisms for long-term improvement in chronic pain patients. The finding that catastrophizing and fear of movement were related to care seeking (**Chapter 4 and 5**) is in line with earlier findings that levels of catastrophizing in people with pain from the general population were lower than in clinical samples [26]. As about only half of the people with (TMD-)pain complaints seek care for their pain [27], and especially those who seek care show higher levels of catastrophizing and fear of movement (**Chapter 4 and 5**), the results could also suggest that theories on the development of chronic pain like the fear-avoidance model, might be biased by the group that is mostly studied (care seekers). That is, clinicians may develop an image of chronic pain patients being avoidant and worried about their complaints, which is more related to care seeking behavior than to the chronic pain itself.

The finding that six-month improvement was negatively related to the number of healthcare practitioners visited before (**Chapter 6**), might be an expression of the difficulties care practitioners have in setting a clinical diagnosis. This is confirmed in the interview study (**Chapter 5**), where care seekers often described that it was difficult to get an adequate referral for their pain complaints. Possibly, not finding adequate care leads to more concerns about the complaints in those who keep seeking care. Or, just the other way around, those with more concerns continue to seek help (**Chapter 4**). Either way, in the time that patients are searching for help, pain complaints last and sensitization processes evolve, which, in turn, complicates treatment.

## Future Directions

This study was performed in the context of the Dutch health care system. In this system, the national health insurance is an obligatory insurance for everyone who falls under the scope of the Dutch social insurance obligation. It contains a standard package of the necessary care (medical care by general practitioners, specialists and midwives, most medication, and nursing care). Dentistry and physiotherapy are not included in the standard package, however, most of the Dutch population has an expanded package that includes dental care and physical therapy [28]. Since in The Netherlands, specialized care is not freely accessible, the participants that were recruited at a TMD-centre, were referred by a general practitioner, a dentist, or another specialist. Although participants declared in the interviews (**Chapter 5**) that financial aspects did not play a role in their motivation to (not) seek care, it would be interesting to investigate whether the findings are generalizable for other countries with an advanced economy such as The Netherlands.

This study revealed some interesting aspects that play a role in the development of TMD-pain and subsequent care seeking behavior. However, as mentioned before, it is notable that as in other questionnaire studies, only few characteristics were identified. Possibly, the only few answers that were gained until now, is a result of the research designs. That is, despite the wide variety of factors that were incorporated in questionnaire studies, still many other possibilities are unexplored. Possibly, studies with different perspectives provide more insights. Broadening our view, some interesting findings show up in literature. For example, there is some evidence that chronic pain conditions cluster in families [29] [30]. Twin studies have reported heritability estimates for back pain ranging from 30% to 57% [31] [32]. Also for TMD-pain, a recent study has provided evidence for a genetic vulnerability for TMD-pain [33]. To improve current knowledge on the mechanisms involved in the critical early stage of the development of chronic pain, the role of genetic variability in this specific pain stage, in combination with clinically relevant information from the biopsychosocial model should be further investigated. Subsequently, this line of research may lead to better treatment strategies to prevent the transition from acute to chronic pain. For example, when patients with a high risk for the development of chronic pain are already recognized at an early stage, patient-tailored treatment strategies can be offered, which may include a multidisciplinary treatment at a relatively early stage [34] [35]. Another perspective was presented recently by Gale et al. who reported that children with lower intelligence are at greater risk of chronic pain later in life [36]. Based on a longitudinal population based-study with a large sample size ( $N > 6000$ ), they were the first to show lower intelligence as a risk factor for chronic pain, independently from socioeconomic position, body mass index and other covariates. The authors suggest that people with poorer mental abilities may be less able to interpret bodily symptoms correctly, leading to an increased risk of developing pain complaints [37].

## Clinical Implications

The findings of this thesis have some implications for healthcare that is provided for TMD-patients. First, the questionnaires that were developed for this research (Patient-Specific Approach for TMD, **Chapter 2**) and the Social support Pain Questionnaire (**Chapter 3**), have gained interest in other research fields and were adapted by practitioners working with chronic pain and TMD-pain. For example, in software programs for physiotherapists, the PSA for TMD-pain complaints is being included as one of the available tools. Comparable to the use of the PSA for low back pain, which is now used in national guidelines for physiotherapist [38], the PSA for TMD-pain complaints could be recommended to be used in future guidelines for orofacial pain, as it was found to predict 6-months improvement. Second, because care seekers showed to be more worried about their complaints than non-care seekers, it is important for health practitioners who treat TMD-pain patients to verify the beliefs about their pain complaints. This finding underlines the importance of reassurance as it might be an essential part of treatment need.

Third, as the interviews showed that some of the non-care seekers were not referred adequately (**Chapter 5**), it is recommended to give more attention to referral directions for health care providers, and to promote postgraduate-courses, in which recognizing TMD-complaints and referral options for TMD-patients are emphasized. Therefore, it is promising that the newly developed guideline for orofacial pain will be released soon[39]. The guideline was developed by an expert group of medical specialists who are all involved in patients with orofacial pain, including the fields of neurology, oral surgery, dentistry and physical therapy. The guideline provides an overview of different disorders causing orofacial pain, and offers referral directions for health care providers [39].

Fourth, adequate information on the Internet may help people to find their way to a health care provider, as both non-care seekers and care seekers (**Chapter 5**) reported that they searched the Internet for information. This suggestion is supported by an earlier report on health care seeking behavior on the Web [40], which pointed out that the information found on the Web has a direct influence on the decisions people make about their health care and also on their interactions with the health care practitioners [40]. TMD-pain sufferers would be helped if TMD-clinics provide the Internet with high quality, evidence-based information regarding TMD. Moreover, since this study confirmed earlier findings [41], that care seekers experience relief in finding fellow-sufferers, patients could be facilitated to come across fellow sufferers. Possibly, and as an addition to a treatment program, group sessions of pain sufferers or Internet communities could offer a platform where patients can meet fellow sufferers. Finally, the result suggest that when the following yellow flags are present in a patient: (a) long pain duration, (b) the patient has visited many healthcare practitioners or (c) high levels of hindrance on function as measured with the PSA (**Chapter 2**), prognosis for treatment is poor (**Chapter 6**). For these patients, multidisciplinary approaches in

which the psychologist plays an essential part, are best fitted to offer these patients strategies in how to cope with pain.

### **Conclusions**

Besides from the intensity of the pain complaint, care seekers are more alarmed by their complaints than non-care seekers. This is expressed in higher levels of fear of movement and more catastrophical thoughts in care seekers as compared to non-care seekers. Moreover, within the subsample of care seekers, also the continuous search for help (as expressed by the number of healthcare practitioners they had visited) is mainly related to the level of catastrophizing thoughts and use of pain medication, and not influenced by the pain intensity.

Besides from pain duration, patients who have visited many healthcare practitioners and who show higher levels of hindrance in function (as measured with the Patient Specific Approach), have a higher risk of persisting pain complaints at 6-months follow-up.

Surprisingly, biopsychosocial factors like social support, depression and somatization were not found to be related to neither care seeking nor improvement.

## References

- [1] Carlsson GE, Magnusson T, Egermark I. Prediction of demand for treatment of temporomandibular disorders based on a 20-year follow-up study. *J Oral Rehabil.* 2004;31: 511-7.
- [2] Egermark I, Carlsson GE, Magnusson T. A 20-year longitudinal study of subjective symptoms of temporomandibular disorders from childhood to adulthood. *Acta Odontol Scand.* 2001;59: 40-8.
- [3] Egermark I, Magnusson T, Carlsson GE. A 20-year follow-up of signs and symptoms of temporomandibular disorders and malocclusions in subjects with and without orthodontic treatment in childhood. *Angle Orthod.* 2003;73: 109-15.
- [4] Macfarlane TV, Blinkhorn AS, Davies RM, Kincey J, Worthington HV. Factors associated with health care seeking behaviour for orofacial pain in the general population. *Community Dent Health.* 2003;20: 20-6.
- [5] Palla S. A need to redefine chronic pain? *Journal of orofacial pain.* 2006;20: 265-6.
- [6] Campbell LC, Clauw DJ, Keefe FJ. Persistent pain and depression: a biopsychosocial perspective. *Biol Psychiatry.* 2003;54: 399-409.
- [7] Epker J, Gatchel RJ. Coping profile differences in the biopsychosocial functioning of patients with temporomandibular disorder. *Psychosomatic medicine.* 2000;62: 69-75.
- [8] Loeser J D, Bonica J, J. Bonica's management of pain Lippincott Williams & Wilkins 2001: p. 2178.
- [9] Main CJS, C.C. Pain management: an interdisciplinary approach Elsevier 2001.
- [10] Von Korff M, Dunn KM. Chronic pain reconsidered. *Pain.* 2008;138: 267-76.
- [11] Adler RH. Engel's biopsychosocial model is still relevant today. *Journal of psychosomatic research.* 2009;67: 607-11.
- [12] Engel GL. The need for a new medical model: a challenge for biomedicine. *Science (New York, NY).* 1977;196: 129-36.
- [13] Main CJ, Watson PJ. Psychological aspects of pain. *Man Ther.* 1999;4: 203-15.
- [14] Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain.* 2000;85: 317-32.



- [15] Dworkin SF, LeResche L. Research diagnostic criteria for temporomandibular disorders: review, criteria, examinations and specifications, critique. *J Craniomandib Disord.* 1992;6: 301-55.
- [16] Arrindell W, Ettema J. Handleiding bij een multidisciplinaire psychopathologie-indicator. Lisse 1986.
- [17] Stomp-van den Berg SGM, Vlaeyen JWS, ter Kuile MM, Spinhoven P, van Breukelen G, Kole-Snijders AMJ. Pijn Coping en Cognitie Lijst. Available at: <http://www.pijn.com/medici/index5.htm>. 2001
- [18] Visscher CM, Ohrbach R, van Wijk AJ, Wilkosz M, Naeije M. The Tampa Scale for Kinesiophobia for Temporomandibular Disorders (TSK-TMD). *Pain.* 2010;150: 492-500.
- [19] Beurskens AJ, de Vet HC, Koke AJ, Lindeman E, van der Heijden GJ, Regtop W, et al. A patient-specific approach for measuring functional status in low back pain. *J Manipulative Physiol Ther.* 1999;22: 144-8.
- [20] Beurskens A, Koke A, de Vet H. Patiëntspecifieke benadering bij het meten. In: R Ostelo, A Verhagen, H de Vet, eds. *Onderwijs in wetenschap Lesbrieven voor de fysiotherapeut*. Houten/Diegem: Bohn Stafleu Van Loghum 2002: p. 55-8.
- [21] Ramond A, Bouton C, Richard I, Roquelaure Y, Baufreton C, Legrand E, et al. Psychosocial risk factors for chronic low back pain in primary care--a systematic review. *Fam Pract.* 28: 12-21.
- [22] Pincus T, Burton AK, Vogel S, Field AP. A systematic review of psychological factors as predictors of chronicity/disability in prospective cohorts of low back pain. *Spine.* 2002;27: E109-20.
- [23] Borghouts JA, Koes BW, Bouter LM. The clinical course and prognostic factors of non-specific neck pain: a systematic review. *Pain.* 1998;77: 1-13.
- [24] Wideman TH, Adams H, Sullivan MJ. A prospective sequential analysis of the fear-avoidance model of pain. *Pain.* 2009;145: 45-51.
- [25] Leeuw M, Goossens ME, Linton SJ, Crombez G, Boersma K, Vlaeyen JW. The fear-avoidance model of musculoskeletal pain: current state of scientific evidence. *Journal of behavioral medicine.* 2007;30: 77-94.
- [26] de Boer MJ, Struys MM, Versteegen GJ. Pain-related catastrophizing in pain patients and people with pain in the general population. *European journal of pain.* 16: 1044-52.

- [27] Macfarlane TV, Blinkhorn AS, Davies RM, Worthington HV. Association between local mechanical factors and orofacial pain: survey in the community. *J Dent.* 2003;31: 535-42.
- [28] den Dekker JA, EJAA. Signalement Mondzorg 2010. Diemen: College voor zorgverzekeringen 2010.
- [29] Edwards PW, Zeichner A, Kuczmierczyk AR, Boczkowski J. Familial pain models: the relationship between family history of pain and current pain experience. *Pain.* 1985;21: 379-84.
- [30] Arnold LM, Hudson JI. Comment on: Familial aggregation of depression in fibromyalgia: a community-based test of alternative hypotheses, Raphael et al., *Pain* 110 (2004) 449-460. *Pain.* 2004;112: 409-10; author reply 10.
- [31] MacGregor AJ. The heritability of pain in humans. In: JS Mogil, ed. *The genetics of pain Progress in pain research and management.* Seattle: IASP Press 2004: p. 151-70.
- [32] Battie MC, Videman T, Levalahti E, Gill K, Kaprio J. Heritability of low back pain and the role of disc degeneration. *Pain.* 2007;131: 272-80.
- [33] Plesh O, Adams SH, Gansky SA. Temporomandibular joint and muscle disorder-type pain and comorbid pains in a national US sample. *Journal of orofacial pain.*25: 190-8.
- [34] Maixner W, Diatchenko L, Dubner R, Fillingim RB, Greenspan JD, Knott C, et al. Orofacial pain prospective evaluation and risk assessment study--the OPPERA study. *J Pain.*12: T4-11 e1-2.
- [35] Fillingim RB, Slade GD, Diatchenko L, Dubner R, Greenspan JD, Knott C, et al. Summary of findings from the OPPERA baseline case-control study: implications and future directions. *J Pain.*12: T102-7.
- [36] Gale CR, Deary IJ, Cooper C, Batty GD. Intelligence in childhood and chronic widespread pain in middle age: the National Child Development Survey. *Pain.*153: 2339-44.
- [37] Bogaerts K, Van Eylen L, Li W, Bresseleers J, Van Diest I, De Peuter S, et al. Distorted symptom perception in patients with medically unexplained symptoms. *J Abnorm Psychol.*119: 226-34.
- [38] Bekkering GH, HJM Oostendorp, RAB Clinical guidelines in physiotherapy for low back pain are published [in Dutch: Richtlijn Lage-rugpijn gepubliceerd]. *FysioPraxis.* 2001;4: 28-31.

[39] Nederlandse Vereniging voor Hoofdpijn Patiënten in samenwerking met beroepsverenigingen. Chronische Aangezichtspijn. Multidisciplinaire richtlijn (in ontwikkeling). Amersfoort, NVVHP, 2013.

[40] Fox S. Health information is a popular pursuit online. 2011. Available at: [http://www.sahs.uth.tmc.edu/evbernstam/HI6308\\_Materials/PIP\\_Health\\_Report.pdf](http://www.sahs.uth.tmc.edu/evbernstam/HI6308_Materials/PIP_Health_Report.pdf)

[41] Durham J, Steele J, Moufti MA, Wassell R, Robinson P, Exley C. Temporomandibular disorder patients' journey through care. Community Dent Oral Epidemiol.39: 532-41.



## **Chapter 8**

### **Summary**

"Temporomandibular disorders" (TMD) is a collective term used to describe a group of musculoskeletal conditions occurring in the temporomandibular region. TMD shares features with other chronic musculoskeletal syndromes (such as low back pain and neck pain) including pain, limited range of motion and hindrance in function. About half of the people with TMD-pain complaints seek care for their complaints. Common treatments that are used are: counseling, physiotherapy and oral appliances, from which most patients benefit. As with other musculoskeletal pain disorders, most patients with an acute TMD pain show fast recovery, regardless of treatment. Especially in those patients with long lasting complaints, treatment success becomes difficult to achieve. In patients who develop persistent complaints, pain can have far-reaching consequences. That is, chronic pain may not only impair physical function, but may also result in mental and emotional difficulties and a diminished quality of life. To improve patient care, particularly for those with long lasting pain complaints, much can be gained by further understanding of the factors that influence the development of chronic pain. Therefore, the aim of this thesis was to improve the understanding of the role of biopsychosocial factors in the development of TMD-pain complaints and care seeking behavior.

For this purpose, a questionnaire survey was conducted among a sample of participants with TMD pain. The questionnaire aimed to cover a wide range of potentially important biopsychosocial factors. Many instruments were available to be implemented in the questionnaire: the so-called "Characteristic Pain Intensity" (CPI) was used to measure pain intensity, the "Symptom Check List 90" (SCL-90) was used to measure depression and somatization, and coping strategies like catastrophizing were measured by the "Pain Coping and Cognition List" (PCCL). Two instruments, that were considered important for this purpose, were not readily available and needed to be developed. These were the so-called "Patient-Specific Approach" (PSA) measure, and a measure for social support in pain patients.

In **Chapter 2** the development of the "Patient-Specific Approach" (PSA) is described. The PSA is based upon an instrument that is widely used in treatment evaluation of patients with other musculoskeletal complaints, like low back pain or neck pain. It rates the amount of hindrance that patients perceive while performing the activity that is most important to them in their daily life, which is hindered because of their jaw complaints, on a Visual Analogue Scale (VAS). First, the activities chosen on the PSA in a sample of TMD patients were evaluated. Second, the clinometric properties of the VAS scores of the PSA, in terms of reproducibility and responsiveness were determined. At treatment start, TMD patients from the department of Oral Kinesiology of ACTA were asked to report the most important activity which is impaired due to their TMD complaints. The amount of hindrance during this activity was rated on a Visual Analogue Scale (VAS). During two follow-up measurements, patients rated the VAS and appraised their overall complaints in terms of 'much worsened', 'slightly worsened', 'remained stable', 'slightly improved', or 'much improved'. Of the 132 patients who fulfilled baseline measurements, 13% reported an activity that is not included in existing TMD-disability questionnaires. The reproducibility of the VAS scores of the 78 patients who

reported that their complaints had 'remained stable' at second measurement, was good (ICC=0.73). At third measurement, the number of patients who had improved and those who did not was about equal. The responsiveness of the PSA was high (AUC=0.91), and the cutoff score for important improvement, where sensitivity (0.85) and specificity (0.84) were as much as possible the same, was 58%: a decrease in VAS score of 58% can be considered an important improvement. Since the activity that is most important to the TMD patient is not always included in existing measurements, and the VAS score of the PSA has good reproducibility and responsiveness, the PSA is a promising tool in TMD-treatment evaluation.

In **Chapter 3**, a new pain-relevant social support instrument, the "Social Support and Pain Questionnaire" (SPQ), was presented, together with an evaluation of its psychometric properties. Satisfaction with social support (pain-relevant social support) may influence behavior in chronic pain patients. In prior studies on measurement of social support, however, commonly instruments that measure social support in daily-life situations are used, rather than pain-specific instruments. A literature search was performed to establish different aspects of social support. For each of the six aspects found, one item was selected for inclusion in the new questionnaire. The draft version of the instrument was field-tested. Thereafter, the psychometric properties of the SPQ were assessed in 250 orofacial pain patients. These subjects were referred to the department of Oral Kinesiology of ACTA or to one of the other six participating Centres for Dental Care in The Netherlands. Principal component analysis showed that the SPQ had a one-factor structure. The test-retest reliability of the SPQ (in a subsample of 54 patients) was fair to good. Convergent validity, as compared with a non-specific social support instrument, was good (N=140; R=0.54;  $p<0.001$ ). The SPQ is a valid and reliable instrument, which offers the possibility to explore the patient's satisfaction with pain-related social support. With the SPQ, a useful tool to assess the influence of social support in various types of pain patients is provided.

The newly developed instruments (PSA and SPQ) were then implemented in a baseline questionnaire. This questionnaire was set out amongst subjects with TMD-pain complaints in seven TMD-clinics in The Netherlands, and in a non-clinical population sample. First, biopsychosocial characteristics of those who did seek care for their TMD-pain complaints (care seekers), were compared to those who did not (non-care seekers) (**Chapter 4**). Additionally, the group of care seekers was further studied with respect to the number of care practitioners they had attended for their TMD complaints. This enabled us to study whether the biopsychosocial profiles varied with increasing complexity of the care seeking behavior. To study which predictive variables were associated with the decision to seek care and with the number of care practitioners attended, multiple regression models were built. Two-hundred-and-three persons with TMD pain (in this chapter referred to as orofacial pain) participated in the study. Of these participants, 169 (140 females) had visited at least one healthcare practitioner (care seekers), while the other 34 persons (25 females) did not (non-care seekers). The decision to seek care was not only associated with pain intensity ( $p<0.05$ ), but, in women, also

with fear of jaw movements ( $p < 0.01$ ): women with more fear of jaw movements were more likely to seek care. Possibly, the absence of the association between fear of movement and care seeking was due to the low number of male non-care seekers ( $N=9$ ). Pain intensity and disability were not associated with the number of health care practitioners attended. Instead, the main predictors were catastrophizing ( $p=0.004$ ) and the use of painkillers ( $p=0.008$ ). It was concluded that pain intensity and fear of jaw movements play an important role in the decision to seek care for TMD-pain. The continuous search for help is associated with catastrophizing and the use of painkillers.

Moreover, in **Chapter 5**, to further investigate differences between care seekers and non-care seekers, semi-structured interviews were held with 16 subjects with TMD-pain complaints: 8 care seekers and 8 non-care seekers, matched for age, sex, pain intensity and fear of jaw movement were selected from the preceding study sample (**Chapter 4**). The interviews were audio-taped, transcribed verbatim and analyzed according to qualitative content analysis. From the analysis, seven themes differentiating care seekers from non-care seekers were identified: "catastrophizing", "pain management", "assertiveness", "critical attitude towards healthcare", "confidence in medical care", "recognition" and "adequate referral".

Finally, it was investigated whether biopsychosocial factors at baseline also influence the 6-month rehabilitation of TMD-pain (**Chapter 6**). Half-a-year after their recruitment, participants of the survey study who were recruited at a TMD-centre (**Chapter 4**), received a follow-up questionnaire. Most of these patients had received treatment within this time period. Based on this questionnaire, participants were classified as "improved" or "not improved". Then, to study which predictive variables were associated with improvement, multiple regression models were built. From the 129 patients that responded to the baseline questionnaire, 100 patients also filled in the follow-up questionnaire (85% female, mean age (years)  $\pm$ SD =  $46.0 \pm 13.8$ ). Fifty percent of these subjects had improved at the 6-month follow-up. Pain duration was the strongest (negative) predictor for 6-month improvement ( $p=0.009$ ). Also the number of care providers visited before ( $p=0.017$ ), and the degree of hindrance on function as measured with the PSA ( $p=0.045$ ) were negative predictors for improvement. No evidence was found to support the role of psychological or social factors on the improvement in patients with a report of TMD pain.



## Conclusion

Besides from the intensity of the pain complaint, care seekers are more alarmed by their complaints than non-care seekers. This is expressed in higher levels of fear of movement and more catastrophical thoughts in care seekers as compared to non-care seekers. Moreover, within the subsample of care seekers, also the continuous search for help (as expressed by the number of healthcare practitioners they had visited) is mainly related to the level of catastrophizing thoughts and use of pain medication, and not influenced by the pain intensity.

Besides pain duration, patients who have visited many healthcare practitioners and who show higher levels of hindrance in function (as measured with the Patient Specific Approach), have a higher risk of persisting pain complaints at 6-months follow-up.

Surprisingly, only few associations are found between biopsychosocial factors and care seeking or improvement.



## Samenvatting

"Temporomandibular Disorders" (TMD) is een verzamelnaam voor een aantal musculoskeletale aandoeningen in de temporomandibulaire regio. TMD toont overeenkomsten met andere chronische musculoskeletale aandoeningen (zoals lage rugpijn en nekpijn), bijvoorbeeld op het gebied van pijnklachten en bewegings- en functiebeperkingen. Ongeveer de helft van de mensen met TMD-pijnklachten zoekt behandeling voor hun klachten. Veel voorkomende behandelingen zijn counseling, fysiotherapie en splinttherapie. Net als bij andere musculoskeletale pijnaandoeningen, tonen de meeste patiënten met acute TMD-pijn snel herstel, al dan niet na behandeling. Echter, wanneer pijnklachten aanhouden, wordt het bereiken van behandelingsucces moeilijker. Bij patiënten die aanhoudende klachten ontwikkelen, kan pijn verstrekkende gevolgen hebben: chronische pijn kan niet alleen een verslechtering van lichamelijke functies tot gevolg hebben, maar ook leiden tot psychische en emotionele problemen en een verminderde kwaliteit van leven. Om patiëntenzorg te verbeteren, vooral voor patiënten met langdurige pijnklachten, kan er veel gewonnen worden door een beter begrip van de factoren die de ontwikkeling van pijn beïnvloeden. Het doel van deze thesis was dan ook om de rol van biopsychosociale factoren op het ontwikkelen van TMD-pijn en het gedrag ten aanzien van het behandelingsproces te onderzoeken.

Met dit doel is een vragenlijststudie opgezet onder mensen met TMD-pijnklachten. De vragenlijst was erop gericht om een uitgebreide reeks biopsychosociale factoren die mogelijk van invloed konden zijn op het ontstaan van langdurige klachten en op het behandelingsproces in kaart te brengen. Voor de meeste factoren, waren meetinstrumenten beschikbaar: Zo kon de "Characteristic Pain Intensity" (CPI) gebruikt worden om de pijnintensiteit te meten, de "Symptom Check List 90" (SCL-90) voor het meten van depressie en somatisatie, terwijl copingstrategieën als catastroferen zijn gemeten met de "Pain Coping and Cognition List" (PCCL). Voor twee factoren die mogelijk ook van belang zijn, waren nog geen instrumenten beschikbaar, en moesten deze nog worden ontwikkeld. Dit waren de zogenaamde "Patient Specific Approach" (PSA) en een meetinstrument om sociale steun bij pijnpatiënten te meten: de "Social Support and Pain Questionnaire" (SPQ).

In **Hoofdstuk 2** wordt de ontwikkeling van het meetinstrument "Patient Specific Approach" PSA voor TMD-klachten beschreven. De PSA is gebaseerd op een instrument dat al langer wordt gebruikt in de behandel-evaluatie van patiënten met andere musculoskeletale aandoeningen zoals lage rugpijn en nekpijn. Het meet de mate van hinder (op een visuele analoge schaal, VAS), die patiënten ervaren bij het uitvoeren van die activiteit die het meest belangrijk voor hen is, en die beperkt is ten gevolge van de kaakklacht. Allereerst werden de activiteiten die een steekproef van TMD-patiënten van de afdeling Orale Kinesiologie van het ACTA noteerden geëvalueerd. Vervolgens werden de klinimetrische eigenschappen, in termen van reproduceerbaarheid en responsiviteit, van de VAS bepaald. Bij de start van behandeling noteerden de TMD-patiënten de gehinderde activiteit. De mate van hinder bij het uitvoeren van deze activiteit werd gemeten met behulp van de VAS. Vervolgens werd op twee follow-up momenten

opnieuw de VAS afgenomen, en werd tevens gevraagd of hun klachten: “erg verslechterd”; “iets verslechterd”, “gelijk gebleven”, “iets verbeterd” of “erg verbeterd” waren. Van de 132 patiënten die aan de eerste meting deelnamen, rapporteerde 13% een activiteit die niet wordt genoemd in reeds bestaande lijsten die beperkingen in activiteiten bij TMD-klachten meten. De reproduceerbaarheid van de 78 patiënten die tijdens de tweede meting aangaven dat hun klachten “gelijk gebleven” waren, was goed ( $ICC=0.73$ ). Tijdens de derde meting waren ongeveer evenveel mensen verbeterd als niet verbeterd. De responsiviteit van de PSA was hoog ( $AUC=0.91$ ), en de cut-off score voor verbetering, waar sensitiviteit (0.85) en specificiteit (0.84) zoveel mogelijk gelijk waren, was 58%. Dat wil zeggen dat een vermindering van 58% op de VAS voor de PSA een belangrijke verbetering is. Aangezien de activiteit die het belangrijkste is voor de TMD-patiënt, niet altijd in bestaande lijsten voorkomt, en de VAS-scores van de PSA een goede reproduceerbaarheid en responsiviteit tonen, is de PSA een veelbelovend instrument voor het evalueren van TMD-behandelingen.

In Hoofdstuk 3 wordt een instrument, de “Social Support and Pain Questionnaire” (SPQ) en zijn psychometrische eigenschappen gepresenteerd. De mate waarin mensen tevreden zijn met de sociale steun die zij ontvangen wanneer zij pijn ervaren, is mogelijk van invloed op het gedrag van mensen met chronische pijn. Voorafgaande studies naar het meten van sociale steun hebben zich echter beperkt tot het gebruik van instrumenten die sociale steun meten tijdens het dagelijks leven, in plaats van pijnspecifieke instrumenten. Er is gezocht naar literatuur om verschillende aspecten van sociale steun te verwerven. Voor elk van de in totaal 6 aspecten die werden gevonden, werd 1 item geselecteerd en opgenomen in het instrument. Nadat een eerdere versie in de praktijk werd getest, werden de psychometrische eigenschappen van de SPQ getoetst in 250 patiënten met orofaciale pijn. Deze deelnemers zijn gerecruteerd bij de afdeling Orale Kinesiologie van ACTA of van een van de andere 6 participerende TMD-klinieken in Nederland. Hoofdcomponentanalyse wees uit dat de SPQ een 1-factor structuur heeft. De test-hertest-betrouwbaarheid (in een subgroep van 54 patiënten) was redelijk tot goed ( $R=0.70$ ;  $p<0.001$ ). De convergent validiteit, vergeleken met een reeds bestaande niet-specifieke sociale steun lijst, was goed ( $N=140$ ;  $R=0.54$ ;  $p<0.001$ ). De SPQ is een valide en betrouwbaar meetinstrument, dat de mogelijkheid biedt om de tevredenheid van patiënten met pijngerelateerde sociale steun in kaart te brengen.

De nieuw ontwikkelde instrumenten (PSA en SPQ) werden vervolgens geïmplementeerd in een baseline vragenlijst. Deze baseline vragenlijst werd verspreid, zowel onder patiënten van 7 TMD-klinieken als onder mensen met TMD-pijn klachten buiten de klinieken (algemene bevolking). Allereerst werden mensen die behandeling zochten (“care seekers”) vergeleken met mensen die geen behandeling zochten (“non-care seekers”) (**Hoofdstuk 4**). Vervolgens werd de groep die behandeling zocht verder bestudeerd ten aanzien van het aantal behandelaars dat zij raadpleegde. Dit stelde ons in staat om te onderzoeken of biopsychosociale profielen varieerden bij een toename van de complexiteit van het behandeling zoeken. Multiple regressie modellen werden gebouwd om te onderzoeken welke voorspellende factoren geassocieerd zijn met het besluit om behandeling te zoeken en met het aantal behandelaars dat werd bezocht.

Twee-honderd-en-drie personen met TMD-pijn (in dit hoofdstuk verwoord als orofaciale pijn) deden mee aan de studie. Hiervan hadden 169 (140 vrouwen) minstens één behandelaar bezocht (care seekers), terwijl 34 personen (25 vrouwen) dat niet hadden gedaan. Het besluit om behandeling te zoeken was niet alleen geassocieerd met de pijnintensiteit ( $p < 0.05$ ), maar, bij vrouwen, ook met angst om de kaak te bewegen ( $p < 0.01$ ): vrouwen met grotere angst om hun kaak te bewegen zochten eerder behandeling. Waarschijnlijk was het ontbreken van deze associatie bij mannen een gevolg van het lage aantal mannelijke non-care seekers ( $N=9$ ). Pijn en beperkingen waren niet geassocieerd met het aantal zorgverleners dat bezocht was. Catastrofen ( $p=0.004$ ) en het gebruik van pijnstillers ( $p=0.008$ ) waren dat daarentegen wel. We concludeerden dat pijnintensiteit en angst om de kaak te bewegen een belangrijke rol spelen bij het al dan niet behandeling zoeken. De mate waarin iemand behandeling zoekt is geassocieerd met catastrofen en het gebruik van pijnstillers.

Vervolgens, om het verschil tussen “care seekers” en “non-care seekers” nog verder te onderzoeken, werden, in **Hoofdstuk 5**, semi-gestructureerde interviews gehouden met 16 personen met TMD-pijn die werden geselecteerd uit de voorafgaande vragenlijststudie (**Hoofdstuk 4**): 8 “care seekers” en 8 “non-care seekers”. Zij werden gematched op leeftijd, geslacht, pijnintensiteit en angst om de kaak te bewegen. De interviews werden opgenomen (audio-opname), vervolgens werd hiervan een verbatim uitgeschreven, en geanalyseerd volgens de methodiek van “qualitative content analysis”. Uit deze analyse kwamen zeven thema’s naar voren waarin “care seekers” verschillen van “non-care seekers”: “catastrofen”, “pijn management”, “assertiviteit”, “kritische houding tegenover zorg”, “vertrouwen in zorg”, “erkenning” en “adequate verwijzing”.

Tot slot werd onderzocht of biopsychosociale factoren ook van invloed zijn op het herstel van TMD-pijn na 6 maanden (**Hoofdstuk 6**). Een half jaar nadat de deelnemers de baseline vragenlijst hadden ontvangen, ontvingen zij een follow-up vragenlijst. De meeste deelnemers hadden in de tussentijd een behandeling gehad. Op basis van deze lijst werden mensen geassocieerd als “verbeterd” of “niet verbeterd”. Vervolgens werd een multiple regressie model gebouwd om te bestuderen welke voorspellende factoren geassocieerd waren met herstel. Van de 129 patiënten die deelname aan de baseline vragenlijst, vulden 100 patiënten ook de follow-up vragenlijst in (85% vrouw, gemiddelde leeftijd (jaar)  $\pm SD = 46.0 \pm 13.8$ ). Vijftig procent van deze deelnemers toonde verbetering bij follow-up. Pijnduur was de sterkste negatieve predictor voor herstel ( $p=0.009$ ). Daarnaast waren ook het aantal voorafgaand bezochte behandelaars en de mate van functiebeperkingen (gemeten met de “Patient Specific Approach”) negatieve predictoren voor herstel. Er werd geen bewijs gevonden voor de invloed van psychologische of sociale factoren op het herstel van TMD-pijn.

## Conclusie

Naast de intensiteit van de pijnklacht, zijn “care seekers” meer verontrust over hun klachten dan “non-care seekers”. Dit wordt uitgedrukt in hogere niveaus van angst om de kaak te bewegen en meer catastrofale gedachten bij “care seekers” dan bij “non-care seekers”. Bovendien, binnen een subgroep van “care-seekers”, bleek ook dat het voortdurend zorg zoeken (uitgedrukt in het aantal behandelaars dat iemand in het verleden heeft bezocht) met name gekoppeld is aan de mate waarin iemand catastrofale gedachten heeft, en niet beïnvloed wordt door de pijnintensiteit.

Naast de pijn duur hebben patiënten die al veel zorgverleners hebben geraadpleegd en die hogere niveaus van functiebeperking hebben (gemeten met de PSA), een hoger risico op het persisteren van pijnklachten na 6 maanden.

Verrassend is dat weinig associaties zijn gevonden tussen biopsychosociale factoren en het zoeken van behandeling of het verbeteren van pijnklachten.

### **List of publications**

A. Rollman, R. Gorter, CM. Visscher, M. Naeije Why seek treatment for TMD pain? A study based on semi-structured interviews. *Journal of Orofacial Pain*, Volume 27, number 3, 2013, 227-34

A. Rollman, CM. Visscher, R. Gorter, M. Naeije Improvement in patients with a TMD-pain report. A 6-month follow-up study. *Journal of Oral Rehabilitation*, Volume 40, issue 1, 2013, 5-14

A. Rollman, CM. Visscher, R. Gorter, M. Naeije Care seeking for orofacial Pain. *Journal of Orofacial Pain*, Volume 26, nr 3, 2012, 206-14

C. van der Lugt, A. Rollman, M. Naeije, F. Lobbezoo, CM. Visscher Social support in chronic pain: development and preliminary psychometric assessment of a new instrument. *Journal of Oral Rehabilitation*, Volume 39, issue 4, 2012, 270-6

A. Rollman, CM. Visscher, M. Naeije The reproducibility and responsiveness of a patient-specific approach: a new instrument in evaluation of treatment of temporomandibular disorders. *Journal of Orofacial Pain*, Volume 24, number 1, 2010, 101-5



### List of presentations

28th Conference, Society of Oral Physiology, Store Kro Club, May 26th to 29th, 2013, Amsterdam, The Netherlands. Oral Presentation: "The complexity of chronic pain. Improvement and care seeking for temporomandibular (TMD) pain complaints. A PhD-thesis overview." by A. Rollman, CM. Visscher, R. Gorter, M. Naeije

27th Conference, Society of Oral Physiology, Store Kro Club, May 26th to 29th, 2011, Torino-Italy. Oral Presentation: "The decision to seek treatment for orofacial pain: a qualitative approach" by: A. Rollman, R. Gorter, CM. Visscher, M. Naeije

Annual meeting of The Netherlands Institute for Dental Sciences (IOT), Lunteren, February 11th and 12th, 2010. Oral presentation: "The decision to seek treatment for orofacial pain: a qualitative approach" by: A. Rollman, R. Gorter, CM. Visscher, M. Naeije

26th Conference, Society of Oral Physiology, Store Kro Club, May 7th to 10th, 2009, Dresden-Germany. Poster Presentation: "Factors related to the number of treatments in people with orofacial pain" by A. Rollman, CM. Visscher, R. Gorter, M. Naeije

Dutch Society for Gnathology and Prosthetic Dentistry (NVGPT) meeting, Academic Centre for Dentistry Amsterdam (ACTA), Amsterdam, The Netherlands, Wednesday, October 7th, 2009: "To seek or not to seek?" by A. Rollman, CM. Visscher, R. Gorter, M. Naeije

25th Conference, Society of Oral Physiology, Store Kro Club, May 24th to 27th, 2007, Naantali-Finland. Oral Presentation: "The reproducibility and responsiveness of a Patient Specific Approach: A new instrument in TMD-treatment evaluation" by A. Rollman, CM. Visscher, M. Naeije

24th Conference, Society of Oral Physiology, Store Kro Club, June 2nd to 5th, 2005, Reykjavik-Iceland. Poster presentation: "Reproducibility of a Visual Analogue Scale" by A. Rollman, CM. Visscher, M. Naeije



## **Dankwoord**

Oktober 2013

En nu is het zover, het is af, het mag naar de drukker. Tijd om afstand te nemen en terug te blikken. Aldoende overheerst een besef dat het doen van dit promotie-traject een fantastische mooie en leerzame periode is geweest. Destijds had ik me niet ten volle beseft waar aan begonnen te zijn, en *moest* ook in het sociaal leven nog van alles ontdekt worden. Tot aan nu, in toenemende mate zelfbewust van mogelijkheden (en onmogelijkheden) en rust en voldoening. Hopelijk toch niet volwassen?! Met name nadat een studie naar therapie-effect (na al een aanzienlijke inspanning) geannuleerd werd, was het pittig om vol te houden. Maar na een periode van tegenslag, kwam er ook altijd weer een periode waarin het voor de wind ging.

Alhoewel dit proefschrift niet heeft kunnen aantonen dat sociale steun invloed heeft op het al dan niet herstellen van pijn, kan ik u wel aan de hand van mijn eigen casus, omschrijven hoe sociale steun mij geholpen heeft bij het afronden van mijn proefschrift, en daarmee lijden verzacht heeft. Dit proefschrift was dan ook niet mogelijk geweest zonder de steun van vrouw, familie, vrienden en collega's. Hierbij wil ik een aantal mensen in het bijzonder bedanken:

Prof. Dr. Ir. M. Naeije, beste Chiel, je altijd heldere analytische blik tijdens onze werkbijeenkomsten ben ik meer en meer gaan waarderen, en is, nu we elkaar met mindere frequentie zien, (zelfs) iets wat ik mis. Ik moet natuurlijk even refereren aan het luxaflex-moment. Ik zal het niet uitvoerig beschrijven, je weet wat ik bedoel. Het belangrijkste is dat dit, denk ik, voor ons een moment is geweest vanaf wanneer we echt goed contact kregen. Ik voel me vereerd dat ik zo nauw met je heb samengewerkt en je heb leren kennen als iemand om in vertrouwen te nemen.

Dr. C.M Visscher, beste Corine, ik kwam in jouw deskundige handen tijdens een wetenschappelijke stage van de opleiding fysiotherapie. Het was vooral de wetenschap dat jij mijn directe begeleider zou zijn tijdens het promotie-traject, dat ik ja zei. Met nog evenveel bewondering als toen kijk ik naar de manier waarop je in staat bent om vanuit een natuurlijke rust te beredeneren en beargumenteren. Fijn dat ik zo vaak bij een zo'n getalenteerde wetenschapper mocht zijn!! En heerlijk hoe we konden lachen als er hele alinea's waar ik op had lopen broeden verdwenen. "Schrijven is schrappen!" was dan altijd je geruststellende boodschap. Ik hoop dat we in de toekomst ruimte vinden om te blijven samenwerken.

Dr. R.C Gorter, beste Ronald, natuurlijk doet onderzoek altijd weer wat langer dan van te voren bedacht, maar relatief gezien is het toch best snel gegaan sinds jij bij het onderzoek bent betrokken. Een gouden greep dus. De sociaal psychologische invalshoek is iets wat goed bij mij past, en jouw kijk op de zaak was altijd verrijkend en verfrissend. Ook op je kijk op hoe om te gaan met werk: Meer levensvreugde door iedere 6 weken vakantie te nemen, is een goed advies dat ik van je zal pogen over te nemen.

Prof. dr. Lobbezoo, beste Frank, alhoewel je niet heel direct bij mijn onderzoek betrokken was, ben je altijd wel op de achtergrond als steun en toeverlaat aanwezig geweest. Je hebt me gesteund door interesse te tonen in mijn opvattingen en door vertrouwen in mij te hebben als fysiotherapeut. Je correctheid en beleefdheid is oprecht, op een manier die ik niet eerder ben tegengekomen! Die unieke eigenschap van je is iets wat ik bewonder. Studenten aansporen om 1 min voor tijd aanwezig te zijn is een trucje dat ik van je gestolen heb.

Dr. G. Aarab, lieve Ghizlane, kamergenoot zowel op ACTA als op congres. Wat kennen we elkaar alweer lang! We deden tegelijkertijd onderzoekstage bij ACTA, en zijn sindsdien maatjes. Vanuit onze verschillende achtergronden zijn er een hoop verschillen tussen ons. Ook los van onze achtergronden zijn we behoorlijk anders: Jij verdenkt kamermeisjes van sabotage van schoonmaak-items, ik doe mee aan modderpoelraces. Maar we vinden altijd een gemeenschappelijkheid in de dingen waar het echt om gaat, waar word je gelukkig van; doe je wat goed voor je is...etc. Vooral onze reisjes voor congres of huwelijk, zitten als warme herinnering op de harde schijf opgeslagen. Er is ruimte voor meer.

Dr. M. Koutris, lieve Micha(i)el(i)s}, colleeegaaa! Ik schrijf in het Nederlands, met wat mooie uitdrukkingen die je op kunt zoeken. We gingen gelijk op naar onze promotie-datum, jij net iets eerder dan ik, gefeliciteerd! We zaten gedurende dit traject in hetzelfde schuitje, en konden daardoor altijd goed bij elkaar het hart uitstorten op de momenten dat we tegen de wind in moesten. We moesten allebei onze aandacht verdelen tussen onderzoek en praktijk, jij ging daarbij ook nog regelmatig naar je gezin in Griekenland. Je zou denken dat een mens dan genoeg aan zijn hoofd heeft, maar jij staat daar ook nog eens voor een ieder klaar en geeft zorg en aandacht aan een ieder die het nodig heeft. Ook ik heb meermaals bij je aangeklopt met mijn ziel onder de arm, en je was er dan gewoon. Daar dank ik je voor.

Dhr. P. Wetselaar, lieve Peter, nog zo'n fijne colleeeega! Wat heerlijk dat je er bent. Met je opgewektheid ben je een enorme kracht voor de vakgroep. Met Miranda en de kids vorm je een mooi gezin. Ik hoop nog vaak binnen en buiten ACTA met je op te trekken. Vooral zie ik uit naar een bustocht met 30 graden door een mooie stad. Peter: BEDANKT!

Dr. M. van Selms, beste Maurits, je doorzettingsvermogen is een groot voorbeeld voor mij. Op de Louwesweg zaten we tegenover elkaar en hebben we samen de muren beschilderd. In IJsland zijn we met Ghizlane op roadtrip geweest. Een warme herinnering waarvan ik in het bijzonder blij ben dat we die reis met jou konden maken.

Dr. van der Zaag, beste Jacques, ook al hebben we niet meer zo'n frequent contact als op de Louwesweg, denk ik dat je weet dat ik je zeer waardeer om je klinische expertise en veel steun heb gehaald uit onze borrelmomenten. Dank!

Dr. M. van der Meulen, beste Marylee, ik heb altijd erg genoten van je patientenverslagen, en de wijze waarop je op voor jouw typerende wijze, over je leesbril

heenkijkend, je indrukken van de patient verwoordde. Wendy is inmiddels jouw opgevolgd. Ik hoop van harte de multidisciplinaire samenwerking in de toekomst voort te zetten.

Dr. W. de Boer, beste Wim, op de Louwesweg zat je rechtsachter mij op de kamer. Je onuitputtelijke bron van kennis op medisch gebied maar ook je brede interesse in kunst, muziek, fotografie en eigenlijk alles, was fantastisch om aan te boren. Met veel plezier bewaar ik een stapel krantenknipsels die je voor mij hebt uitgekozen.

Dr. S. Kalaykova, beste Stani, zowel op de Louwesweg als nog even in het nieuwe gebouw een trouwe kamergenote. Ik realiseer me dat ik bijna ben vergeten dat je geen native Dutch speaker bent, hoe zeg je dat in het Nederlands? Ik wil je in het bijzonder bedanken voor het helpen met het werven van de 'non-care seekers' in het vondelpark.

Ook alle andere kamergenoten, in het bijzonder Konstantin, Eiko, Kranya en Herman, wil ik bedanken voor de leuke momenten.

Beste Carlijn van der Lugt, ook met jou ben ik op pad geweest voor het werven van 'non-care seekers'. Met jouw rode cabrio gingen wij het land door. Ook wil ik je bedanken voor de fijne samenwerking aan het artikel over social support.

De studenten fysiotherapie van de HvA wil ik graag bedanken voor hun bijdrage aan dit proefschrift. Ook wil ik graag alle 'oude' en 'nieuwe' masters met in het bijzonder Chryssa Papagianni bedanken voor hun verfrissende input tijdens en buiten werkbesprekingen.

Zonder de ondersteuning van Els die honderden brieven en vragenlijsten heeft verstuurd en geadministreerd en de hulp in en rond de kliniek van Samara, Hanneke, Elaine, Rianne, Francis, Inge, Hannah, en Mariëtte, was dit proefschrift niet mogelijk geweest. Bart, al wat langer geleden heb je me geholpen met de technische zaken rondom slaapregistraties. Ook voor vernuftigheden op de computer kon ik altijd bij terecht. Tineke en Ko, de pensionadas, dank jullie wel!

De centra voor bijzondere tandheelkunde die mee hebben gedaan aan dit onderzoek wil ik bedanken voor hun inzet.

Het IOT, in het bijzonder Vincent Evers, Martijn van Steenberg en Martine Meijer, wil ik bedanken voor de steun gedurende dit onderzoek.

Speciale dank gaat uit naar alle patienten en "non-care seekers" die mee hebben gedaan aan dit onderzoek. Ook wil ik hen die aan onderzoek dat niet direct tot publicaties heeft geleid, graag bedanken voor hun bereidwilligheid om extra tijd en moeite investeren voor dit onderzoek.

Lieve Karlijn, samen met jou heb ik invulling gegeven aan een carrière naast mijn promotie-onderzoek. Dit was hard nodig want er moest geld verdiend worden. Het

optuigen van oesh(.nl) heeft me veel ruimte en creativiteit geboden om te gaan ondernemen. We gaan nu op werkgebied ieder onze eigen weg, gelukkig niet in de wegstaand dat we goede vrienden zijn gebleven. Fijn dat je er bent! OESH

Lieve Maryam, via Corine (ook hiervoor bedankt Corine) hebben wij elkaar leren kennen, en heb je mij gevraagd om je collega te worden bij het ergonomie- en CMD-onderwijs bij de opleiding mondzorgkunde. Ik geniet altijd van de gelijkenis die wij hebben in de visie op ons vak en in de manier waarop we in het leven staan. Ik ben blij dat we bij elkaar in de buurt wonen, zodat we elkaar nu ook buiten het werk wat gemakkelijker tegen kunnen komen. Ook alle collega's van InHolland, met in het bijzonder Truus de Bruijn, Margiet Ottens, Chris Gommers en Jacqueline van Rennes, wil ik bedanken voor hun betrokkenheid.

Beste Marinus, Eddy en Istvan en Jan, dank jullie wel dat jullie me hebt geholpen van het opzetten van mijn eigen praktijk bij Corpus Vitae en Nassaukade 57. Ook wil ik alle collega's van beide praktijken bedanken voor het werkplezier.

Beste Bart, dank je wel dat je mij hebt geïntroduceerd in de commerciële kant van het ondernemerschap. Met onze verschillende kwaliteiten vormen we een goed team. Ik hoop dat ik nog veel voor FysioFirst kan betekenen.

Beste Multidisidenters, ik hoop dat we nog vele voedzame, euh leerzame bijeenkomsten hebben!

Beste Rinus, je bent voor mij een mentor en inspirator. Je inspireert me om kritisch te kijken naar mijn eigen handelen en te beseffen dat ik nooit ben uitgeleerd. Ik ben je heel dankbaar voor de lessen die ik van je gehad heb tijdens de Leergang Coaching, nog dankbaarder ben ik dat je contact met me hebt gehouden en dat we nog regelmatig bij elkaar komen om te kijken hoe ook in de fysiotherapie/ zorg een solution focus benadering zou passen.

Dear Susan and Vijay, it is great to have you as (yoga)teachers in my life.

Familie Rollman en familie Bralten wil ik graag bedanken voor het verzorgen van een warm nest. In het bijzonder wil ik de familie Rollman-Verheijen voor de heerlijke wintersporten samen die bijna jaarlijks voor welkome ontspanning en plezier zorgen.

Lieve lieve, vriendjes en vriendinnetjes, de andere familie. Ik noem geen namen want dan vergeet ik iemand, en worden de drukkosten te hoog: Voel je genoemd. In jullie bijzijn ben ik nooit heel erg bezig met mijn proefschrift of werk. Misschien heb ik wel meer tijd met jullie doorgebracht dan mijn (co-)promotoren lief was. En toch is het mede door die afwisseling van werelden dat het onderzoek doen niet saai is geworden. Dank jullie wel voor de afleiding, inspiratie, plezier, leven.

Lieve Han & Yvonne en Sascha, ik wil jullie bedanken voor de steun die jullie mij en Bauke geven. Dank jullie voor het luisterend oor en vragen stellen. Nieuwe familie erbij, fijn!

Lieve Wieneke, fijn dat ik zo'n warme band heb met je. Je bent voor mij een rots in de branding. We hebben inmiddels allebei een partner (mijn man is een vrouw, zou oma Ali gezegd zeggen) waardoor we misschien iets minder elkaar nodig hebben als steun en toeverlaat dan een paar jaar terug. Als het nodig is, ben je er voor me. Om je gelukkig te zien met Chris en Otis in jouw leven, maakt ook mij gelukkig.

Lieve papa & mama, voor jullie maakt het niet uit of ik promoveer of niet. Dat maakt jullie niet onverschillig, maar zorgt voor een gevoel van onvoorwaardelijkheid: ik ben goed zoals ik ben. Ik zou niet meer of minder gelukkig zijn als dit niet gebeurd was, dan was er wel iets anders gebeurd waar ik ook gelukkig mee zou zijn, een diepe wijsheid, die jullie mij hebben meegegeven. Ik dank jullie daarvoor.

Allerliefste Bauke, toen je in mijn leven kwam wist ik dat jij hetgeen was wat ik *moest* ontdekken. Het ontbrekende puzzelstukje. Ik leerde je kennen in de zomer dat ik vragenlijsten uit moest zetten. Aangezien dit op openbare plekken moest zijn, en jij op het stadstrand Blijburg was te vinden, ben ik daar ook maar daar (geheel belangeloos) gaan recruteren. Sinds ik met jou ben, ben ik efficiënter gaan werken, en meer haast gaan maken. We hebben nog veel plannen. Gedurende mijn promotie was jij er voor me als ik 's nachts wakker werd en het niet meer zag zitten om dat hele stuk nog te schrijven. Je relativerende opmerkingen en mij erop wijzen dat "het al goed is" waren van doorslaggevend belang om door te zetten. Dank je wel lief!







