

# Why Seek Treatment for Temporomandibular Disorder Pain Complaints? A Study Based on Semi-structured Interviews

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***Aims:** To assess possible differences between care seekers and non-care seekers with temporomandibular disorder (TMD) pain complaints, by using semi-structured interviews. **Methods:** Semi-structured interviews were held with 16 subjects who had 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 audiotaped, 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 health care, 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. The use of semi-structured interviews may further improve insights into processes that determine care seeking among people with TMD pain complaints. J OROFAC PAIN 2013;27:227–234. doi: 10.11607/jop.1081*

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

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.<sup>6,7</sup> It was shown that higher levels of pain intensity increased the probability of seeking care.<sup>6,7</sup> Higher levels of fear of jaw movement were also positively related to care seeking.<sup>7</sup> 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,<sup>1,3,8–10</sup> it is likely that the reasons for care seeking in subjects with TMD pain share similarities with the reasons for care seeking in subjects with other musculoskeletal pain conditions. In the literature related to care seeking for low back pain, 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.<sup>11,12</sup> However, individuals with low physical disability or only mild pain also were found to have visited a health care practitioner, indicating that indeed other factors are involved in the decision to seek care as well.<sup>13</sup>

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 such as semi-structured interviews are powerful in discovering perceptions of people that may remain unnoticed in closed-answer questionnaire studies.<sup>14,15</sup> Therefore, the aim of the present study was to assess possible differences between care seekers and non-care seekers with TMD pain complaints through the use of semi-structured interviews. Subjects were selected from a previous survey study.<sup>7</sup>

## Materials and Methods

### Subjects

The subjects 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.<sup>7</sup> 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<sup>7</sup> had shown that pain intensity (as measured on a characteristic pain intensity scale)<sup>16</sup> and fear of jaw movements (as measured with a fear-of-jaw-movement scale)<sup>7</sup> 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 matched for age and sex comparable to the distribution in the previous survey study.<sup>7</sup> The medical ethical committee of the VU University of Amsterdam approved the study (file number 2004/166).

### Semi-structured Interviews

In alternating rounds, care seekers and non-care seekers were interviewed in a nonclinical environment: either at the participant’s home, at the Oral Kinesiology Department office, or in a quiet public location, depending on the participant’s preference. Each participant was interviewed for about 30 to 60 minutes, and the interview was digitally audiotaped (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.<sup>17</sup>

The interviews were designed to enable people to respond in an unrestricted way, allowing aspects to be introduced by respondents and by the interviewer.<sup>18</sup> The interviews had the following structure: an introduction in which the principal investigator gave an explanation about the goal of the interview and in which she asked the subject about his or her TMD pain complaints (eg: “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 (eg: “So, could you tell about what kind of care you sought for this pain?”) to bring the conversation to health care 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; this was done through 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
- Health care usage for other (pain) complaints
- Experiences in health care 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 the literature,<sup>6,11,12</sup> it could be expected that they play a role in care seeking. To be sure that the information given by the participant was correctly and completely understood, the principal investigator ended the interview with a summary, 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,<sup>19</sup> whereby data collection and analysis occur concurrently, allowing previous propositions to be explored in subsequent interviews. This method was used, and data collection continued until no new issues emerged from the interviews (and saturation was achieved).<sup>19</sup> After seven non-care seekers and seven care seekers were interviewed, 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 (one with an MSc in Oral Public Health and with a dental education background; one 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.<sup>20,21</sup> 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, with no knowledge of 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

**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.

to comment on the themes in two ways. First, they were asked 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.

### Results

As a result of the matching procedure, the eight non-care seekers did not differ from the eight care seekers with respect to age, sex, pain intensity, and fear of jaw movements. In both groups, the non-care seekers and the care seekers, six women and two men participated (Table 1). All participants who 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, and one theme was related to external circumstances. In the following section, these themes are more fully described. Citations, illustrating the description, are noted in italics.

**Table 2** Summary of the Themes Differentiating Care Seekers from Non-Care Seekers for TMD Pain Complaints

	Care seeker	Non-care seeker	No. of experts that found this theme independently (round 1)
<b>Characteristics</b>			
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

**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 as 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, had a tendency to manage their pain themselves; in fact, 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 was 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 did not want to bother someone else with their complaints. They felt uncomfortable when consulting a health care practitioner. Non-care seekers tended to keep the pain to themselves and did not want to complain. To them it felt like they were exaggerating when consulting a health care 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 instead 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 they 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 being 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 their general practitioner gave them; and all wished that the general practitioner would have been more directive (or more quickly directive) in referring to a health care provider.

## Discussion

The aim of this study was to assess possible differences between care seekers and non-care seekers for TMD pain complaints through the use of semi-structured interviews. In a previous study, it was shown that pain intensity and fear of movement are related to care seeking.<sup>7</sup> This study indicated that care seeking may also be associated with differences in person-related characteristics: catastrophizing, pain management, assertiveness, critical attitude towards health care, confidence in medical care, and recognition. Moreover, non-care seekers reported that they were not always adequately referred to a health care provider. These results indicate that semi-structured interviews may provide further insights into processes that determine care seeking among persons with TMD pain complaints.

In the present interview study, two methodological aspects may have influenced the results. First, due to the small sample size, there is 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.<sup>19</sup> 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 pair was interviewed, which also did not provide new information, suggesting that indeed saturation had been achieved. A second risk is that personal notions and expectations of the experts analyzing the interviews may have influenced the results (bias). Whereas most qualitative research studies used one or two experts to analyze the data,<sup>18,22,23</sup> in this study the risk of bias was minimized by using a Delphi-consensus method with a panel of five experts.<sup>20,21</sup> Four of them were psychologists, three of whom were also professionally active in dentistry, thus providing 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 of care seeking in subjects with TMD pain complaints performed to date,<sup>18,22,23</sup> the motivations and experiences of care seekers only were investigated. A unique aspect of the present study was that a group of non–care seekers in addition to care seekers was interviewed. Since non–care seekers did not report their complaints at a health care office, and therefore are 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,<sup>7</sup> in which about 100 people had to be approached face-to-face at public places in order to find 1 non–care seeker with TMD pain complaints. Interestingly, the topics that were expected to play a role in care seeking, based upon the 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, better and more diverse insights into factors influencing care seeking were obtained than when merely looking at care seekers. The fact that non–care seekers reported that because of an inadequate referral they sometimes did not receive treatment for their complaints, could only be found by interviewing non–care seekers.

To the best of the authors' knowledge, studies of care seeking in subjects with TMD pain<sup>4,6,7</sup> or low back pain<sup>11</sup> that included non–care seekers as a control group always used 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.<sup>4,6,7,11</sup> The present study was likely the first to have used the technique of semi-structured interviews, where participants were invited to talk freely about their personal pain history, resulting in them describing yet unknown aspects of care seeking. The present interview study revealed that in addition to what has been found in questionnaire studies, person-related characteristics play a role in care seeking. For example, the study revealed that care seekers seemed critical of and not easily satisfied with accessible care, and were persistent in searching for adequate care, which was not found in the previous literature. This underlines the strong asset of in-depth interviews: They offer new information to 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.<sup>24</sup> It is encouraged that in the future, studies with a similar 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 gave 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 a result of expecting solutions from others, they appear assertive, are critical, and look for recognition. This study separated the characteristics as different, rather broad, concepts (pain management, assertiveness, critical attitude, and recognition). Future studies could give insight into whether these characteristics are a consequence of the subjects' locus of control (internal or external).

Interestingly, non–care seekers in contrast to care seekers appeared not so concerned about their pain, but most of them had chronic pain complaints. This seems to be in disagreement with the fear-avoidance model by Vlaeyen and Linton, which suggests that catastrophizing is an important precursor of chronic pain.<sup>25</sup> As a reaction to a painful injury, a vicious circle of pain, catastrophizing, fear of movement, and disability is thought to lead to the development of a chronic pain condition.<sup>25</sup> In favor of this theory is a recent clinical trial that showed the therapeutic efficacy of an early biopsychosocial intervention for patients with acute TMD who are at risk of developing chronic TMD; it demonstrated that pain levels dropped significantly after the biopsychosocial intervention, as assessed at the 1-year follow-up.<sup>26</sup> The present 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. They keep trying to find a solution on their own, 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,<sup>27</sup> 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 health care practitioners.<sup>27</sup> This indicates that TMD clinics should provide the Internet with high-quality, evidence-based information regarding TMD. Moreover, since this study confirmed earlier findings<sup>22</sup> that care seekers experience relief in finding fellow sufferers, patients should be encouraged to seek out 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 was that not only person-related characteristics are of influence on the care seeking of subjects with TMD pain complaints, but also external circumstances play a role. Adequate reactions or referrals of health care practitioners who encounter patients with TMD pain complaints are important. The interviews showed that a non-care seeker may be a non-care seeker because he or she was not adequately referred. Moreover, and in line with a previous study,<sup>22</sup> care seekers often reported they had traveled a long way through the health care system before actually finding their way to a TMD health care provider. This confirms that not every health care provider is aware of the treatment possibilities for TMD problems.<sup>28</sup> As suggested by others, clear guidelines and education programs for dentists and other health care practitioners should be promoted to increase knowledge on TMD care and TMD treatment possibilities.<sup>29,30</sup>

## Conclusions

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 health care, confidence in medical care, and recognition. In addition to these characteristics, it was found that inadequate referrals may play a role in care seeking. The use of semi-structured interviews can provide additional insight to the internal processes that determine care seeking among people with TMD pain complaints.

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