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

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Chapter 3

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

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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 ± SD [range] = 41.7 ± 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 (α=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 ($n = 250$)

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

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.

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References


