# Accepted for publication in Clincal Journal of Pain, 12.1 2011 Fibromyalgia Patients' Communication of Cues and Concerns -Interaction Analysis of Pain Clinic Consultations

Hilde Eide<sup>1,2\*</sup>, PhD Tonje Sibbern<sup>2,3</sup>, MA Thore Egeland<sup>2,4</sup>,PhD Arnstein Finset<sup>5</sup>, PhD Tone Johannessen<sup>6</sup>, RN Christine Miaskowski<sup>7,8</sup>, PhD Tone Rustøen<sup>2,8</sup>,PhD

<sup>1</sup>Current main position: Buskerud University College, Department of Health Sciences,

Drammen

<sup>2</sup> Oslo University College, Faculty of Nursing, Oslo

<sup>3</sup> Diakonhjemmet University College, Oslo

<sup>4</sup> University of Oslo, Institute of Forensic Medicine

<sup>5</sup> University of Oslo, Department of Behavioral Sciences in Medicine

<sup>6</sup> Oslo University Hospital, Aker Pain Clinic

<sup>7</sup> University of California, San Francisco

<sup>8</sup> Oslo University Hospital, Rikshospitalet

\*Corresponding author: Professor Hilde Eide Department of Health Science, Buskerud University College PoBox 7053, N-3007 Drammen Fax. +47 32206410 e-mail: <u>Hilde.Eide@ hibu.no</u>

Original article

Key words: fibromyalgia, communication, cues, concerns, empathy, clinician-patient relations

# Acknowledgements

The authors would like to thank all of the patients who participated in this study as well as all of the clinicians at the Aker Pain Clinic, Oslo University Hospital who enrolled the patients and did the data collection.

The project was funded by grants from the Norwegian Research Council (158707), Faculty of Nursing Oslo University College, and the Norwegian Fibromyalgia Society.

No conflicts of interest exist.

#### Abstract

**Objectives:** Clinicians' recognition of patients' concerns is an important component of effective treatment and care. During a consultation, patients often do not express their concerns directly, but rather present them indirectly as hints or cues. The aim of this study was to explore the types of concerns and cues patients expressed in an initial consultation with a nurse at a pain clinic, how and who initiated these cues and concerns, and predictors of these expressions.

**Methods:** Initial consultations between patients with fibromyalgia (n = 58, 85% female, duration 30 minutes, mean age 47.8 (SD 10.7) and clinical nurse specialists (n=5) were videotaped. Patients' cues and concerns were coded using the Verona Coding Definitions of Emotional Sequences. Nurses' responses to patients' cues and concerns were evaluated using the Hierarchical Coding Scheme of Comforting Strategies. In addition, pain intensity and duration, overall evaluation of health, affect at the start of the consultation, and psychological distress were evaluated.

**Results:** Patients expressed more cues than concerns, mostly about pain, interpersonal relationships, and/or emotional reactions. Both lack of empathic responding and unspecific empathic responding were associated with the expression of an increased number of cues in the consultation while higher evaluation of health was associated with less cues. More concerns were expressed by patients when nurses exhibited a high level of empathic responding and when the patient entered the consultation with a higher level of negative affect.

**Discussion:** Findings from this study highlight the importance of a patient centered communication style to facilitate the expression of cues and concerns.

#### Introduction

Patients with fibromyalgia syndrome (FMS) experience high levels of unpredictable widespread musculoskeletal pain, tenderness, fatigue, stiffness and sleep disturbance,<sup>1,2,3</sup> as well as anxiety and depression.<sup>4,5,6</sup> In addition, many face socioeconomic consequences including unemployment that results in significant decrements in quality of life (QOL).<sup>7</sup> Effective communication between patients with FMS and clinicians is critical because patients often contact physicians when their symptoms escalate. Many clinicians find it difficult to help them and these patients often express dissatisfaction with their care.<sup>8,9,10</sup>

Recognition of patients' concerns is an important component of effective treatment and care.<sup>11,12</sup> Concerns or expressions of worry represent patients' perspectives about the impact of their health problem and are signals of what the patients want their clinician to address during a consultation.<sup>13</sup> Reasons for less effective and satisfactory communication in patients with FMS may be due to both patient and clinician factors. Data from other patient populations suggest that patients seldom present these concerns in a straightforward way, but more often as emotionally loaded hints or cues that clinicians need to detect.<sup>14,15,16,17</sup> Moreover, findings from several studies suggest that clinicians find it difficult to relate to negative emotions (e.g., anger, sadness) in general<sup>15</sup> and especially to pain expressions.<sup>17,18,19</sup> In addition, findings from several studies suggest that paying attention to patients' pain expressions will reinforce their pain.<sup>19,20,21</sup> Taken together, these findings suggest that both patients and clinicians may avoid direct communication about the patients' concerns which may make it difficult to provide effective treatments for chronic pain or other medical conditions.

Cano and Williams<sup>21</sup> suggested that an intimacy model of interaction may be useful in pain research. This model views talking about thoughts and feelings about pain as emotional self-disclosure and that the response to this communication should match the expressed need in order to be helpful and healthy.<sup>21,22</sup> When a person expresses distressed emotions, it can be hypothesized that the person seeks empathic understanding and emotional support as a response rather than instrumental support (e.g. advice or information). In fact, in one study,<sup>23</sup> patients with medically unexplained symptoms provided many cues related to their desire for emotional support in a consultation with a general practitioner. Another experimental study found that patients with FMS with alexithymia wanted an empathic response from the physician and patients without alexithymia wanted time to express themselves.<sup>24</sup>

4

However, no studies were found that investigated the expressions of cues and concerns in patients with FMS during an initial consultation at a pain clinic and which factors were associated with these expressions. Therefore, the purposes of this study were to explore: 1) how patients express cues to negative emotions and concerns; 2) who (i.e., patient or nurse) initiated these expressions; 3) the specific content of the various cues and concerns; and 4) to what extent and how patient factors, nurse factors, and interpersonal interaction factors were associated with the number of cues and concerns expressed.

#### Methods

#### **Design and sample**

Within a cross sectional, exploratory design, fifty-eight patients referred to an outpatient pain clinic from May 2005 to June 2007 with the diagnosis of FMS and chronic widespread pain were included in this study. The pain clinic performs 800 new patient consultations per year. Approximately 10% of these consultations are for patients FMS. Five experienced nurses (four female and one male) conducted the first consultation interview with these patients. All consultations were videotaped. The patients were informed about the study in their invitation letter to the pain clinic and received a detailed explanation by the nurse before signing the informed consent.

During the study period, seventy-nine patients were evaluated as eligible. The inclusion criteria for this study were: having a referral diagnosis of FMS; being substantially limited by the condition; not responding to traditional treatments under the care of a general practitioner; judged to need the services of a multidisciplinary pain clinic; and having no history of substance abuse. Twenty-one patients declined to participate (75% response rate), because they felt too sick and/or considered the videotaping to be an extra burden. The nurse performing the consultation was responsible for the videotaping. The study was approved by the Regional Committee for Research Ethics and the Norwegian Social Science Data Services (NSD).

Patients were referred to the pain clinic from a general practitioner. The aim of the first consultation was to assess the patients' needs for medical assistance, with a focus on the psychosocial aspects of their condition. All patients completed a standard questionnaire that obtained information on sociodemographic characteristics; pain duration, severity and intensity; psychological distress; how pain influenced daily life; medication use and effectiveness; activities that made pain worse or alleviated pain; and QOL. During the consultation, patients' responses to the questionnaire were discussed with the nurse using a

semistructured format.

#### Coding of cues and concerns

To identify cues and concerns, the 58 videotaped pain clinic consultations were first analyzed by one of the researchers (TS) using the "Verona Coding Descriptions for Emotional Sequences" (VR-CoDES).<sup>25</sup> This coding scheme was developed through a consensus process by an international workgroup called the Verona Network on Sequence Analysis (i.e., a special interest group within The European Association for Communication in Health Care). The goal of the VR-CODES is to standardize the coding and categorization of cues and concerns during health care consultations so that findings can be compared across studies.

The VR-CoDES consists of the elements that are necessary to be able to recognize expressions of implicit and explicit negative emotions (NE),<sup>25</sup> (e.g. emotional intensity, types of linguistically, paralinguistic, and nonverbal expressions). The coding scheme divides the emotional or potential emotional utterances into one category called a "concern" or seven hierarchical categories of "cues to negative emotion". A *concern* is defined as "A clear and unambiguous expression of an unpleasant current or recent emotion where the emotion is explicitly verbalized". A *cue* is defined as: "A verbal or nonverbal hint which suggests an underlying unpleasant emotion and would need a clarification from the health provider".<sup>25</sup> Six of the seven hierarchical categories of cues are listed in Table 1. Number seven is "a clear expression of an unpleasant emotion, which occurred in the past". This code was not used because the coding for this study was completed prior to the addition of this category to the most recent version of the VR-CoDES.

During the coding process, the coder needed to decide whether the cue or concern was initiated by the nurse or the patient in order to identify if the expressed cue or concern was nurse driven or patient driven. If the nurse asked a question related to a specific emotion and the patient agreed (e.g., Nurse: "Do you feel sad?" Patient: "Yes"), this interaction was coded as a concern initiated by the nurse. If the nurse's question led to expression of a cue or concern within the same topic this interaction was also coded as nurse initiated. Cues or concerns with new content not mentioned by the nurse were coded as initiated by the patient.

VR-CoDES were validated through interviews with 12 patients viewing their consultations and identifying when they presented a concern to the nurse<sup>13</sup> A very high degree of sensitivity and specificity was found between VR-CoDES and patients' identification of their concerns.

The reliability between the coders was 0.60 (Cohen's kappa) for cues and 0.82 for concerns, which is characterized respectively as good and excellent.<sup>27</sup> The first ten interviews were coded separately by the two raters and the non overlapping codes were discussed until consensus was reached. Then TS coded the rest of the consultations and HE coded another 8 (14%) for inter-rater reliability calculations.

#### The content of the cues and concerns

The VR-CoDES do not include categories for the specific *content* of the coded cue or concern. Negative emotional reactions can be caused by different problems that patients with chronic pain face. In this study, eight thematic content categories were used to categorize the content of the cues and concerns, based on studies that described the influence of chronic pain on the lives of patients with FMS.<sup>1,2,3,4,5,6,7,28</sup> The eight content areas were: pain experience, medication, life events associated with the pain, sleep problems and energy, other diseases and complaints, relationships, economy and work, and emotional reactions. *Classification of the nurses' empathic responses* 

Applegate and Burleson's instrument called "Hierarchical Coding System for Comforting Strategies" (HCSCS) was used to classify how emotionally attuned the nurses' immediate responses to the cues and concerns were.<sup>29,30,31</sup> This instrument, that was originally based on Carchuff's Empathy Scale<sup>32</sup> describes how one person helps another person in a private social context to handle emotional distress related to a situation.

The HCSCS coding system consists of nine categories that represent three different levels of how a response is attuned to the other person's perspective. The first level is "denial of individual perspective" with three categories (1) the nurse condemns the feelings of the patient; (2) the nurse challenges the legitimacy of the patients feelings; or (3) the nurse ignores the patients feelings. The second level is "implicit recognition of individual perspective" with three categories (4) the nurse attempts to divert the patient's attention from the distressful situation and the feelings arising from that situation; (5) the nurse acknowledges the patient's feelings, but does not attempt to help the patient understand why those feelings are being experienced or how to cope with them; or (6) the nurse provides a non-feeling - centered explanation of the situation and elaboration of individual perspective" with three categories (7) the nurse explicitly recognizes and acknowledges the patient's feelings, but provides only truncated explanations of these feelings; (8) the nurse provides an elaborate acknowledgement and explanation of the patient's feelings; or (9) the

nurse helps the patient to gain a perspective on his or her feelings and attempts to help the patient see these feelings in relation to a broader context or the feelings of others.

In this study responses within the first level were categorized as "lack of empathic responding", within the second level as "medium level of empathic responding" and within the third level as "high level of empathic responding". A sum score of the responses on the three different levels was calculated for each patient.

The second author (TS) evaluated all the responses and assigned a code to each response. The first author (HE) coded 11 consultations (267 responses of 801) for the calculation of inter-rater reliability. The agreement between the coders measured by intra class correlation (ICC) was 0.70 which is evaluated as good.<sup>33</sup> HCSCS was shown to be a reliable and valid instrument in other settings.<sup>29,30</sup>

# Measurement of pain intensity, present emotional state, psychological distress and general health

Least and worst pain intensity were measured during the past 14 days using 0 to 10 numeric rating scales. Just before the consultation, patients completed the Positive and Negative Affect Schedule (PANAS).<sup>11</sup> Positive and negative affect are considered to be the two major dimensions of emotion that can influence the interaction process. The PANAS was developed to include positive and negative affectivity as two separate dimensions, each dimension containing 10 emotional items. Patients were asked to indicate on a five point Likert scale (1=very slightly/not at all to 5=very much) "To what degree does each of the following adjectives describe your feelings or emotional state at the present moment?". Two sum scores were calculated (i.e., positive affect items and negative affect items). The PANAS has well established reliability and validity.<sup>11,34</sup> In this study, Cronbach's alpha for the negative affect subscale were 0.87 and 0.84, respectively.

General health was evaluated with one item from the SF-36 that asked patients to rate "In general, would you say your health is" on a 1 (excellent) to 5 (bad) scale.<sup>35</sup> This item was used in Norway in a study of patients with non-malignant pain <sup>7</sup> as well as in a general population study.<sup>36</sup>

Psychological distress was measured with Hopkins Symptom Check List (SCL-25)<sup>37,38,39</sup> which consists of 25 items that evaluate two dimensions of psychological distress, namely anxiety and depression. Each item was scored on a Likert scale that ranged from 1 ("not at all") to 4 ("extremely"). Overall psychological distress is the average item score; the sum score of the total number of items divided by the number of items. A cutoff point of 1.75 is often applied as an indicator of mental problems.<sup>40</sup> A mean depression sum score was calculated by averaging the depression items. SCL-25 is a reliable and valid questionnaire.<sup>37,38</sup> In this study, the Cronbach's alphas for the total scale and depression subscale were 0.90, and 0.84, respectively.

#### Data analyses

Data were analyzed using SPSS version 17.0 (SPSS, Inc, Chicago, IL). Descriptive statistics were generated on sample characteristics. Missing items on the different scales were substituted with the mean score of the answered items. Chi-square analyses were used to determine the relationship between the content codes and the different categories of the VR-CoDES. To explore the influence of the FMS symptoms and background factors on the expression of cues and concerns, linear mixed model analyses were applied with cues and concerns as dependent variables, and nurse as a random factor. This method was chosen to control for dependency in the data and to control for possible correlations within the measures. This dependency may arise since one nurse interviewed several patients. First, analyses were done controlling for duration of the consultations to establish possible significant relationships between each predictor variable and the two outcome variables. Then the predictors that had a significance level of p < 0.05 in the bivariate analyses were all entered into the full models with and without interactions.<sup>27</sup> Residual analyses were performed to test if model assumptions were violated.

#### Results

#### Sample characteristics

As shown in Table 2, over 80% of the 58 patients were female, 57.4% were married or living together, and 65.4% were on sick leave or had disability pension.

The nurses had a mean age of 41 years (range 38 - 51). All were clinical nurse specialists; one in mental health, two in intensive care, one in cancer nursing, and one in multicultural nursing. Mean working time at the pain clinic was 6.8 years (range 3-11). *Patients' reported pain, psychological distress, emotional state and general health* 

As shown in Table 3, the mean duration of pain was 14.1 years. Pain intensity scores, measured using a 0 (no pain) to 10 (worst pain) NRS, ranged from 3.7 (least pain) to 9.3 (worst pain). Eighty-one percent stated that the pain started gradually. Psychological distress measured with all SCL-25 items was 2.2, and 75% scored above the cut off of 1.75 that indicates the need for a thorough evaluation of mental health. Negative emotion on the PANAS was 1.61 (indicating "a little") and positive emotion was 2.79 (indicating "a little" to

"moderate" level). Health status was rated at 4.4 (SD 0.88) (indicating "rather bad").

#### Number of and initiation of cues and concerns

The mean duration of the consultations was 36.14 minutes (range 14.25 to 52.30 minutes). As shown in Table 1, a total of 591 cues and 210 concerns were identified across the 58 consultations. Per consultation, the average total number of cues was 10.2 and the average number of concerns was 3.6. Nurses initiated an average of 8.2 cues and 2.0 concerns. Patients initiated 3.0 cues and 0.6 concerns. Most cues were uttered through vague or unspecified words or phrases. Only 3.5% of the cues were nonverbal.

#### Content of cues and concerns

The results of the thematic content coding of each cue and concern are displayed in Table 4. The majority of the cues and concerns were about the pain experience, followed by cues and concerns about emotional reactions and interpersonal relationships. Examples of cues and concerns in one consultation are displayed in Table 5. The cues and concerns are organized according to thematic content. The order of appearance in the consultation is given in parentheses.

#### Nurses responses to patients' cues and concerns

The different types of responses are displayed in Table 6. For both cues and concerns, most of the responses were categorized as a medium level of empathic responding; both as responses to cues as to concerns.

#### Predictors of expression of cues

In order to examine what might predict patients' expressions of cues, a mixed model analysis was performed with the total number of cues as the dependent variable. First a bivariate relationship between duration of consultation and sum of cues was tested (p=0.01). Then predictor variables were tested in mixed model analyses controlling for duration of the consultation. The variables age, civil status, gender, duration of pain condition, worst pain, least pain, economic status, overall psychological distress (sum score SCL-25), depression (depression items SCL-25), positive and negative affect (PANAS), and total number of concerns were not significantly associated with total number of cues. Seven variables with a p-value of < 0.05 (i.e., general health, the sum of patient initiated- and nurse initiated cues and concerns, the three different empathic responding variables and duration of the consultation) were included in the final model (displayed in Table 7). No significant interaction effects were found. In the final model, only three variables remained significant. A higher score on general health led to fewer expressed cues. Both lack of empathic

responding and medium level of empathic responding were significant predictors and were associated with a higher number of expressed cues. Duration of the consultation was not significant in the whole model. No significant effect of nurses was found (p = 0.556) which indicates that the results were not dependent on differences between individual nurses who performed the interviews. Residual analysis indicated that the model assumptions were not violated.

#### Predictors of expression of concerns

To answer the corresponding question of what predicted expression of concerns, the same procedure was undertaken with the total number of concerns as the dependent variable (Table 7). Duration of the consultation was significant in the bivariate analysis (p=0.023). The variables of age, civil status, gender, duration of pain condition, worst pain, least pain, economic status, general health, overall psychological distress, depression, positive affect, total number of cues and lack of empathic responding were not significantly associated with total number of concerns. The variables with a p-value of < 0.05 in the analyses (i.e., negative affect, the sum of patient initiated- and nurse-initiated cues and concerns, medium and high level of empathic responding, and duration of the consultation) were entered into the adjusted analyses to build the final model that controlled for the individual nurse. Only negative affect and high level of empathic responding remained significant in the whole model. Duration of the consultation was not significant. No interaction effects were significant and no significant differences were found among the nurses (p= 0.300). Residual analysis indicated that the model assumptions were not violated.

#### Discussion

This study is the first to evaluate real time communication between fibromyalgia patients and clinicians during an initial consultation in a pain clinic and to apply communication interaction analysis methods to evaluate the content of these consultations. The main findings were that these consultations between nurses and pain patients in an intake interview included many cues and concerns; that patient experiences of pain and emotion were more often expressed in terms of cues than as explicit concerns; and that cues and concerns were predicted by quite different variables.

Compared to most studies of physician-patient communication, the patients with FMS in the present study expressed a large number of cues and concerns.<sup>11</sup> Of note, in a qualitative validation study with twelve of the patients who participated in this study,<sup>13</sup> the cues and concerns identified by the researchers were concordant with the specific concerns that

patients expressed when they were asked directly what problems they wanted the nurses to address during the consultation visit. While few studies of nurse-patient communication are available for comparative purposes, the present findings are similar to a recent study of oncology patients.<sup>16</sup> A variety of factors could contribute to the large number of cues and concerns expressed by FMS patients including: high levels of emotional distress, the number of problems these patients experience, the length of the interview, and the special nature of the interview as an admission interview in a pain clinic with a focus on the psychosocial impact of pain. This finding is supported by previous studies<sup>14,41,42</sup> showing that when clinicians have access to a list of patient's reported problems and preferences, more time is spent on patient's problems. Another factor that might contribute to the large number of cues and concerns is that advanced practice nurses who were specialized in chronic pain management performed these consultations.

Consistent with previous studies of patients with other medical conditions, <sup>12,17,43,44</sup> patients with FMS communicated about their pain and other emotional issues by using different types of cues (74%) rather than by explicit expressions of negative emotions (i.e., concerns (26%)). No linear relationship was found between expressions of cues and concerns. Most cues were related to the pain condition and were expressed in many different ways. For instance in general terms ("my situation is worse"), as metaphors ("pain is torture"), or with emphasis on interpersonal aspects with emotional connotations ("nobody sees that I am in pain"). This communication style poses challenges for clinicians who need to detect patients' cues and make decisions about which cues need to be acknowledged or explored further, and which cues require an intervention. The complexity of FMS, characterized by widespread bodily pain and a high degree of psychosocial distress, makes both the detection of and responses to fibromyalgia patients' communication of cues and concerns an extremely challenging task.

Neither the patients' emotional state pre-interview nor their overall psychological distress were related to number of cues expressed. Concerns, on the other hand, were predicted by patients' level of negative affect at the time of the consultation. Of note, cues and concerns were predicted by different variables. The empathy variables were differentially associated with cues and concerns. While the expressions of cues were associated with "lack of empathic responding" and "intermediate level of empathic responding", concerns were predicted by the number of times the nurse used high level of empathic responding. At first these findings may seem contradictory. However, the association between expressions of

cues and low levels of empathy is consistent with the hypothesis proposed by Suchman et al.,<sup>43</sup> that cues would escalate if they were not acknowledged by the clinician. That "intermediate level of empathic responding" was significant is in alignment with the function of the most often applied nurse response "back-channeling" that implies "go on, tell me more".

The finding that nurses applied more validating and supportive responses in relation to concerns suggests that an intimacy model of communication<sup>21</sup> may be valid in the clinical setting. The nurses' use of empathic responding facilitated expressions in the consultation. We know from our validation study that the cues and concerns identified by the VR-CoDES method were in line with what patients' regard as important topics for the consultation at the pain clinic.<sup>12</sup> Results from other studies suggest that patients with FMS want to tell their story.<sup>23,45</sup> In addition, in a recent study of patients with irritable bowel syndrome,<sup>46</sup> lack of support was associated with poorer health outcomes. In addition, similar to this study, very few demographic or clinical characteristics predicted positive health outcomes. Additional research is warranted to determine whether patient outcomes are enhanced when clinicians engage directly with patients, elicit their concerns, and respond in an empathetic manner. Until these data are available, communication between patients and clinicians can be enhanced by having clinicians listen for cues and concerns, particularly about emotional needs, and respond in a more empathetic manner.

In order to understand more of what constitutes helpful responding in the pain setting patients' own view of clinicians' responses to cues and concerns should be explored in future studies. Furthermore, it seems that the nurses in this study were able to avoid spontaneous reactions (e.g. withdrawal or distancing) in response to all the negative emotions communicated about the pain condition.<sup>17</sup> However, it is not known whether or not these responses facilitated further expression of concerns because only the immediate response to cues or concerns was coded, not the larger sequences. Additional research is needed, that uses both qualitative and statistical sequence analytical methods to determine if applying higher levels of empathic responding influences patients' ongoing expression of negative emotion) expressed.

This study was focusing on nurses, as nurses always were seeing these patients at the clinic and therefore had an important role in the care of these patients. Research has also revealed that nurses are good at taking their patients' perspective, to stand in their patients'

shoes,<sup>47</sup> and in this study responding empathically accurate.<sup>31</sup> However, both nurses and physicians are important for the total care of these patients, and there might be large individual differences in the ability to be empathic for both professions.

Several study limitations need to be acknowledged. Because the study was conducted in a single setting, the findings may not generalize to patients in other pain clinics. Because the sample was primarily female, gender differences in cues and concerns could not be determined and require investigation in future studies. As this study is one of the first to apply VR-CoDES to pain communications, direct comparisons across studies is not possible. Therefore, these findings require replication in patients with FMS and other chronic pain conditions. Since the focus of the paper was to explore how cues and concerns were expressed linguistically, emotionally, and thematically with descriptive statistical methods and possible predictors with linear mixed model analyses, the sequential dimension of communication was not evaluated and should be explored with sequential analytic methods.<sup>48,49</sup> In addition, the lack of associations between various demographic and clinical characteristics and the number of cues and concerns identified needs to be interpreted with caution because of the relatively small sample size. These findings warrant verification in future studies. Finally, no data are available on the patients who chose not to participate in this study. However, the primary reason for refusal was that they thought that the videotaping would be an extra burden. Perhaps these patients were sicker and would have demonstrated differences in their expression of cues and concerns. Future studies need to explore the relationship between physical and mental health status and the expression of cues and concerns

#### **Conclusions and implications**

The patients with FMS in this study presented many statements with emotional overtones, connotations and implications, most often related to pain, and more often expressed implicitly as cues rather than as explicitly expressed emotional concerns. Clinicians need to listen carefully for cues. The empathic responding variables that predicted the number of cues underscores the fact that attuned emotional responses of clinicians (intermediate level of empathic responding for cues and high level of empathic responding for concerns) are crucial for the expression of patients' cues as well as concerns. Findings from this study highlight the importance of a patient centered communication style, with equal weight on active listening and empathic response. A novel finding in this study is how these principles seem to be differentially related to cues and concerns. Therefore, clinicians

need education and skills training to be able to detect patients' cues and concerns and to respond in an empathetic manner to these cues and concerns. The VR-CoDES and the HCCS frameworks could be used to teach clinicians how to respond in a more empathic manner to patients with fibromyalgia.

#### References

- 1. Bombardier CH, Buchwald D. Chronic fatigue, chronic fatigue syndrome, and fibromyalgia. Disability and health-care use. *Med Care*. 1996;34:924-30.
- Goldenberg DL, Burckhardt C, Crofford L. Management of fibromyalgia syndrome. JAMA. 2004;292:2388-95.
- 3. Häuser W, Arnold B, Eich W et al. Management of fibromyalgia syndrome an interdisciplinary evidence-based guideline. *Ger Med Sci.* 2008;6:14.
- 4. Thieme K, Turk DC, Flor H. Comorbid depression and anxiety in fibromyalgia syndrome: relationship to somatic and psychosocial variables. *Psychosom Med.* 2004;66:837-44.
- Arnold LM, Hudson JI, Keck PE et al. Comorbidity of fibromyalgia and psychiatric disorders. *J Clin Psychiatry*. 2006;67:1219-25.
- Lieberman MD, Eisenberger NI, Crockett MJ et al. Putting feelings into words: affect labeling disrupts amygdala activity in response to affective stimuli. *Psycho Sci.* 2007;18:421-8.
- 7. Fredheim OM et al. Chronic non-malignant pain patients report as poor health-related quality of life as palliative cancer patients. *Acta Anaesthesiol Scand*. 2008;52:143-8.
- 8. Asbring P, Narvanen AL. Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Soc Sci Med*. 2003;57:711-20.
- 9. Page LA, Wessely S. Medically unexplained symptoms: exacerbating factors in the doctorpatient encounter. *J R Soc Med*. 2003;96:223-7.
- Alghalyini B. That sinking feeling: a patient-doctor dialogue about rescuing patients from fibromyalgia culture. *Can Fam Physician*. 2008;54:1576-7.
- Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: the PANAS scales. *J Pers SocPsychol*. 1988;54:1063-70.
- Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol Bull.* 2007;133:438-63
- 13. Eide H, Eide T, Rustøen T, Finset A. Patient's validation of Cues and Concerns identified according to Verona Coding Definitions of Emotional Sequences (VR-CoDES). A Video

- and Interview Based Approach. In press, *Pat Educ Counsel.* 2010; http://dx.doi.org/10.1016/j.pec.2010.04.036.

- 14. Detmar SB, Aaronson NK, Wever LD et al. How are you feeling? Who wants to know?
  Patients' and oncologists' preferences for discussing health-related quality-of-life issues.
  *J Clin Onc.* 2000;18:3295-301.
- 15. Sheldon LK, Ellington L, Barrett R et al. Nurse responsiveness to cancer patient expressions of emotion. *Patient Educ Couns*. 2009 76:63-70.
- Uitterhoeve R, Bensing J, Dilven E et al. Nurse-patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-Onc.* 2009;18:1060-8.
- 17. Craig KD, Versloot J, Goubert L et al. Perceiving pain in others: automatic and controlled mechanisms. *J Pain*. 2010;11:101-8.
- Goubert L, Craig KD, Vervoort T et al. Facing others in pain: the effects of empathy. *Pain.* 2005;118,3:285-288
- 19. Goubert L, Vervoort T, Crombez G. Pain demands attention from others: The approach/avoidance paradox. *Pain*. 2009;143,1-2:5-6
- 20. Fordyce, WE. *Behavioral methods for chronic pain and illness*. 1976, CV Mosby, St Louis.
- Cano AM, Williams AC de C. Social interaction in pain: Reinforcing pain behaviors or building intimacy? *Pain*. 2010;149,1: 9-1
- 22. Cutrona CE, Shaffer PA, Wesner KA, Gardner KA. Optimally matching support and perceived spousal sensitivity. *J Fam Psychol*. 2007;21:754-8.
- Salmon P, Ring A, Humphris GM et al. Primary care consultations about medically unexplained symptoms: how do patients indicate what they want? *J Gen Intern Med.* 2009;24:450-6.
- 24. Graugaard PK, Holgersen K, Finset A. Communicating with alexithymic and nonalexithymic patients: an experimental study of the effect of psychosocial communication and empathy on patient satisfaction. *Psychother Psychosom.* 2004;73:92-100.
- 25. Zimmermann C, Del Piccolo L, Bensing J et al. Coding Patient Cues and Concerns in Medical Consultations: The Verona Coding Definitions of Emotional Sequences (VR-CoDES). In press; *Pat Educ Couns*. 2010;doi:10.1016/j.pec.2010.03.017.

- 26. Zimmermann C et al. Verona Coding Definitions of Emotional Sequences (VR-CoDES). Cue and Concern Manual 2009. European Association for Communication in Health Care, 2009, *www.each.nl*.
- 27. Altman DG. Practical statistics for medical research. London: Chapman & Hall, 1997.
- 28. Häuser W, Eich W, Herrmann M et al. Fibromyalgia syndrome: classification, diagnosis, and treatment. *Dtsch Arztebl Int*. 2009;106:383-91.
- 29. Applegate J. Adaptive communication in educational contexts. Com Educ. 1980;29:158-70.
- Burleson BR. Comforting Messages: Features, functions, and outcome. In: Daley J, Wieman J, eds. *Strategic interpersonal communication*. Hilsdale, New Jersey: Erlbaum, 1994:135-61.
- 31. Eide H, Sibbern T, Johannessen T. How empathic accurate are nurses immediate responses to fibromyalgia patients' expressions of negative emotions? Evaluation through interaction analysis. In press, Journal of Advanced nursing.
- Carkhuff R. *Helping and human relations: A primer for lay and professional helpers.* New York: Holt, Rinehart & Winston, 1967.
- 33. Sneeuw KCA, Aaronson NK, Sprangers MA et al. Value of caregiver ratings in evaluating the quality of life of patients with cancer. *J Clin Oncol.* 1997;15:1206-17.
- 34. Strand EB, Zautra AJ, Thoresen M et al. Positive affect as a factor of resilience in the pain-negative affect relationship in patients with rheumatoid arthritis. *J Psychosom Res.* 2006;60:477-84.
- Ware JE, Jr., Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*. 1992;30:473-83.
- 36. Loge JH, Kaasa S. Short form 36 (SF-36) health survey: normative data from the general Norwegian population. *Scand J Soc Med.* 1998;26:250-8
- 37. Derogatis LR, Lipman RS, Rickels K et al. The Hopkins Symptom Checklist (HSCL). A measure of primary symptom dimensions. *Mod Probl Pharm*. 1974;7:79-110.
- Derogatis LR, Lipman RS, Rickels K et al. The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory. *Behav Sci.* 1974;19:1-15.
- Strand BH, Dalgard OS, Tambs K, Rognerud M. Measuring the mental health status of the Norwegian population: a comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). Nord J Psych. 2003;57:113-8.

- 40. Sandanger I, Moum T, Ingebrigtsen G et al. The meaning and significance of caseness: the Hopkins Symptom Checklist-25 and the Composite International Diagnostic Interview. II. *Soc Psychiatry Psychiatr Epidemiol*. 1999;34:53-9.
- 41. Bieber C, Müller KG, Blumenstiel K et al. A shared decision-making communication training program for physicians treating fibromyalgia patients: effects of a randomized controlled trial. *J Psychosom Res.* 2008;64:13-20.
- 42. Detmar SB, Muller MJ, Wever LD et al. Physician communication during outpatient palliative treatment visits. *JAMA*. 2001;285:1351-7.
- 43. Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathic communication in the medical interview. *JAMA*. 1997;277:678-82.
- Eide H, Quera V, Graugaard P, Finset A. Physician-patient dialogue surrounding patients' expression of concern: applying sequence analysis to RIAS. *Soc Sci Med.* 2004;59:145-55.
- 45. Werner A, Malterud K.It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Soc Sci Med*. 2003;57:1409-19.
- 46. Conboy LA, Macklin E, Kelley J, Kokkotou E, Lembo A, Kaptchuk T. Which patients improve: characteristics increasing sensitivity to a supportive patient-practitioner relationship. Soc Sci Med. 2010;7:479-84.
- Fields SK, Hojat M, Gonnella JS, Mangione S, Kane G, Magee M. Comparisons of nurses and physicians on an operational measure of empathy. *Eval Health Prof.* 2004 27:80-94.
- Del Piccolo L, Mazzi MA, Dunn G et al. Sequence analysis in multilevel models. A study on different sources of patient cues in medical consultations. *Soc Sci Med*. 2007;65:2357-70.
- 49. Connor M, Fletcher I, Salmon P. The analysis of verbal interaction sequences in dyadic clinical communication: a review of methods. *Patient Educ Couns*. 2009;75:169-77.

Tabla 1	Distribution	of optogr	mias of	(N = 501)	
	Distribution	of calege		cues (N = 591)	

		Patient	Nurse –
Hierarchical categorization of cues based on the Verona Coding		initiated	initiated
	Descriptions for Emotional Sequences		N (%) <sup>d</sup>
<sup>a</sup> Cue 1	Words or phrases in which the patient uses vague or	<sup>b</sup> 36 (30.7)	186 (39.4)
	unspecified words to describe his/her emotions		
Cue 2	Verbal hints to hidden concerns	29 (24.4)	130 (27.5)
Cue 3	Words or phrases which emphasize (verbally or non-	19 (15.9)	76 (16.1)
	verbally) physiological correlates of unpleasant emotional		
	states		
Cue 4	Neutral utterances that mention issues of potential	17 (14.3)	74 (15.7)
	emotional importance which stand out from the narrative		
	background and refer to stressful life events and		
	conditions		
Cue 5	Patient initiated repetition of a previous neutral expression	4 (3.4)	<sup>e</sup> NA
Cue 6	Nonverbal cues that are clear expressions of negative or	14 (11.8)	6 (1.3)
	unpleasant emotions (crying) or hint to hidden emotions		
Sum		<sup>f</sup> 119 (20)	472 (80)
			L

<sup>a</sup> Each cue label is the specification of the category within VR-CoDES

<sup>b</sup> Number of cue in the specific cell

<sup>c</sup> Percentage of all patient-initiated cues

<sup>d</sup> Percentage of all nurse-initiated cues

<sup>e</sup> The nurse cannot initiate responses in this category

<sup>f</sup>Percentage of the sum of cues

Table 2 Patient characteristics (N=58)

# Gender

Male	9 (15.5%)
Female	49 (84.5%)
Age	47.6 years (SD 10.7) Range 26 -70
Education	n %
Primary (< 11 years)	16 (27.6)
Intermediate (11-13)	years) 25 (43.1)
Higher education (>	13 years) 12 (20.7)
Missing	5 (8.6)
Civil status	
Married/living togeth	ner 31 (57.4)
Not married	8 (14.8)
Divorced / separated	13 (24.1)
Widows	2 (3.7)
Missing	4 (8.5)
Work situation	
Working / education	12 (20.7)
Sick leave / revalidat	ion 22 (34.4)
Disability pension	19 (31.0)
Unemployed	3 (5.2)
Missing	5 (8.6)
Economic situation	
Bad	21 (36.2)
Good	23 (39.7)
Very good	9 (15.5)
Missing	5 ( 8.6)

general health					
Pain duration (years)	mean 14.1, SD 9.9 Range 3 – 46				
	(missing 8 / 13.8 %)				
Pain intensity					
Worst pain	mean 9.3, SD 0.86 Range 7 - 10				
Least pain	mean 3.7, SD 2.08 Range 0 - 10				
Start of pain					
Suddenly	5 (8.6%)				
Gradually	47 (81.0 %)				
Missing	5 (8.6%)				
SCL-25 <sup>1</sup>					
Mean score all items	2.2 (0.5)				
Cases (score $> 1.75$ )	44 (75.9%)				
Mean score for the depression items (13)	2.27 (0.6)				
(5 patients with missing data)					
PANAS <sup>1</sup> (just before the consultation)					
Positive emotions	2.79 (SD 0.78)				
Negative emotions	1.61 (SD 0.73)				
Overall evaluation of health <sup>1</sup>	4.4 (SD 0.88)				
(8 patients with missing data)	(8 patients with missing data)				
<sup>1</sup> Range 0-5					

Table 3 Patient reported pain characteristics, psychological distress, emotional state and general health

		Average per consultation			Concern	Cue
Rank	Topic	Mean	(SD)	Range	N (% of	N (% of cues)
					concerns)	
1	Pain and pain experience	5.0	(3.3)	0-15	60 (28.6)	231 (39.0)
2	Emotional reactions	2.2	(2.7)	0-14	57 (27.1)	80 (13.5)
3	Relationships	1.9	(2.2)	0-13	32 (15.2)	74 (12.5)
4	Sleeping problems and energy	1.1	(1.2)	0-4	12 (5.7)	57 (9.6)
5	Medication	1.0	(1.2)	0-5	21 (10.0)	38 (6.4)
6	Work and economy	1.0	(1.4)	0-5	13 (6.2)	34 (5.7)
7	Other diseases and complaints	0.9	(1.7)	0-7	8 (3.8)	46 (7.8)
8	Life events associated with the pain	0.4	(0.8)	0-3	4 (1.9)	19 (3.2)
9	Other	0.2	(0.5)	0-3	3 (1.4)	12 (2.0)

Table 4 Content of the cues (N=591) and concerns (N=210)

Table 5. A content analysis of one patient's cues and concerns

## The pain and the pain experience

- 1<sup>a</sup> "My situation is worse now"<sup>b</sup> (cue 4, nurse initiated)<sup>c</sup>
- 7 "I am not back to where I was and my pain varies a lot" (cue 3, patient initiated)
- 9 "Pain is torture, worse than ileus" (cue 2, nurse initiated)
- 10 "I have to live with it, I am beyond the thought of suicide" (cue 2, nurse initiated)
- 12 "I have worked my way up, but my body is working itself down" (cue 2, nurse initiated)
- 19 "Nobody sees I am in pain I am trembling inside and I feel nauseated" (cue 3, nurse initiated)

# **Emotional reactions**

- 4 "I doubt I'll get better" (cue 2, nurse initiated)
- 13 "I want to be something" (cue 2, nurse initiated)
- 23 "I will be strong, I will not cry, I have had that thought since I was four" (cue 1, nurse initiated)

# Relationships

- 2 N: "How are you satisfied with your GP?"
  - P: "(*Sighs*) No, (Smiles a bit)" (cue 7, nurse initiated)
- 11 "I have many good and supportive relationships, also my children, but I do not want them to take over my role and be supportive, I am the mother" (cue 4, patient initiated)
- 20 "Visiting my mother is a burden" (cue 2, nurse initiated)
- 21 "I have many old frustrations related to siblings" (concern, nurse initiated)
- 22 "Cannot stand that my sister will be angry" (cue 2, nurse initiated)

# Sleeping problems and energy

- 3 "I have been exercising too much" (cue 2, nurse initiated)
- 24 "I am worn out" (cue 3, nurse initiated)
- 25 "I lay long awake in bed before I fall asleep" (cue 2, nurse initiated)

# Medication

26 "No pain medication has effect" (cue 2, nurse initiated)

### Work and economy

- 5 "Now I am nothing. I have applied for disability pension but not yet got any" "I want to work" (cue 2, nurse initiated)
- 6 "I have still hope that I will be able to work, but that is diminishing" (cue 2, nurse initiated)
- 8 "Frustrated if I have to go into a new rehabilitation work process, I am afraid that I will be

set back" (<sup>d</sup>HE: she gets tasks that are very strain full to her body) (concern, nurse initiated)

15 "I will say no if that is offered again" (HE: and this will of course put her in a nasty economical situation) (cue 1, nurse initiated)

# Other illnesses and complaints

- 17 "Think I have another condition, and I am excited about hearing what the result will be" (concern, nurse initiated)
- 18 "I hope you (HE: the pain clinic) will be able to find out what is wrong with me, and that that is not serious" (cue 2, nurse initiated)
- <sup>a</sup> Order of appearance in the interview
- <sup>b</sup> Patient's expression
- <sup>c</sup> VR-CoDES, codes ( concern or type of cue and who has initiated)
- <sup>d</sup> HE are comments made by the first author

# Table 6 Nurses' responses to patients' cues and concerns

Lack of empathic		Medium level of	High level of	
	responding	empathic responding	empathic responding	
	N (%)	N (%)	N (%)	
Cue sum	78 (13.2) <sup>a</sup>	453 (76.6)	60 (10.2)	
Concern sum	21 (10.0) <sup>b</sup>	145 (69.0)	44 (21.0)	
Total	99 (12.4)	598 (74.7)	104 (13.0)	

<sup>a</sup> % of cues

<sup>b</sup> % of concerns

	Effect estimate C	ues <sup>c</sup>	Effect estimate Concerns <sup>c</sup>	
Dependent variables				
Predictor variables	Bivariate analyses controlling for nurse	Adjusted analysis	Bivariate analyses controlling for nurse	Adjusted analysis
	and duration of		and duration of	
	consultation		consultation	
Negative affect			0.109*	0.120**
General health #	-1.930*	-1.145**		
Total number of				
cues				
Patient initiated	1.217***	NS	1.217***	NS
cues and concerns				
Nurse initiated cues	0.923***	NS	0.923***	NS
and concerns				
Lack of empathic	1,104***	1.603*		
responding				

# Table 7. Mixed model linear analyses of predictors of expression of cues<sup>a</sup> and concerns<sup>b</sup>