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The association between the experience of threats on symptom severity and pain in rheumatic diseases: A concept mapping study



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Abstract

Objective. In rheumatic diseases, threatening factors are assumed to amplify pain and fatigue. In Gilbert's affect regulation theory, threats can be of external or internal nature and are factors that create a feeling of unsafety, harm or danger. The aim of the current study was to identify threats in rheumatic diseases and their association with physical symptoms. *Methods*. An online survey was carried out to identify threats (study 1) in 724 patients from multiple countries. Forty threats were used in a card sorting task in 111 patients with enduring physical symptoms (107 female, mean age 48.41 yrs.; 4 male, mean age 52.50). Participants had to group the cards according to content and severity of the threat.

Results. Hierarchical cluster analysis organized the 40 threats in six overarching clusters: 'Weather', 'Physical factors', 'Social pressure and invalidation', 'Limits', 'Activities' and 'Negative feelings'. In 49 patients with a rheumatic disease (47 female, mean age 53.30 yrs.; 2 male, mean age 53.49 yrs.), 'Physical factors' and 'Social pressure and invalidation' were found to be associated with symptom severity.

Discussion. This study yielded an encompassing set of threats that may amplify somatic symptoms and showed which threats were associated with symptom severity. In clinical practice, this knowledge can be used to screen patients and teach them, how to manage these threatening experiences or to develop self-management tools.

Keywords: Threats, rheumatic diseases, somatic symptoms, symptoms severity, pain, fatigue.

Introduction

In rheumatic diseases, pain and fatigue are prevalent. Half of the rheumatic patients experience severe fatigue that impacts the quality of life (Overman, Kool, Da Silva, & Geenen, 2016). The experience of fatigue for rheumatic patients is closely related to pain. The nature of this pain experience can be driven by multiple factors of different natures (Nikolaus, Bode, Taal, & Van De Laar, 2013). The experience of somatic symptoms can be alleviated as well as worsened by a wide range of factors, such as stress or sleep problems (Fitzcharles, Almahrezi, & Shir, 2005). However, it is yet unclear which psychological factors have a prominent role in alleviating or worsening these. In order to increase the wellbeing of patients with rheumatic diseases, it is important to map the different psychological factors that are associated with somatic symptoms.

Neurological processes are core to the experience of pain and fatigue. Due to an sensitized brain, patients can experience more pain and fatigue. Psychological experiences are thought to influence these neurological processes, and in this way the intensity of pain and fatigue (Pinto et al., 2020). One factor that is thought to be particularly important in the experience of physical symptoms, is the experience of threats (Pinto et al., 2020). Threats are part of the affect regulation theory of Gilbert. This theory states that an individual possesses three systems that are important for the regulation of emotional states, being the threat system, soothing system and motivational system (Gilbert, 2010). In the experience of emotions, people switch between these three systems. The function of the threat system is to identify possible threats and alert and prepare the individual to take action (Gilbert, 2010). The experience of a threat leads to feelings of unsafety and danger. Threats can be of external or internal nature. Threats are thought to worsen patients pain, fatigue or other physical symptoms. This is echoed by Oliveira and colleagues (2009), who examined the experience of pain and quality of life in rheumatic patients. They showed that patients that worried more

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about their symptoms (i.e., perceive them as threatening), experienced more pain. This implies that experiencing something as threatening is associated with the experience of somatic symptoms. Therefore, this current study foreground's Gilbert's affect regulation theory to determine whether threatening factors of different nature are associated with the experience of somatic symptoms.

Multiple studies point towards the importance of cognitive and interpersonal factors that are associated with somatic symptoms. Research from Hewlett et al. (2011) proposed a conceptual model for rheumatic diseases, which states that disease processes, cognitive and behavioral factors, and personal life factors interact in influencing fatigue. The cognitive and behavioral factor is a dynamic model in which feelings, thoughts, behaviors and symptoms interact. Hewlett et al. (2011) identified that illness beliefs, low mood and low self-efficiency are predictors of the experiences of rheumatic fatigue, which are shaped by personal factors such as feelings of personal responsibility, a stressful personal environment or lack of (adequate) social support. Nikolaus et al. (2013) also emphasize cognitive and interpersonal factors. They stated that catastrophic thoughts, avoidant coping styles and interpersonal events are associated with experiencing fatigue. These results are supported by a longitudinal study by Waltz, Kriegel and Van 't Pad Bosch (1998), which states that interpersonal factors such as the social environment and negative spouse behavior were related to pain severity in rheumatic diseases. Thus, these studies indicate that cognitive and interpersonal factors are associated with pain and fatigue experience in rheumatic diseases, and with that support Gilbert's theory (2010) that threatening events may be associated with somatic symptom experience in rheumatic diseases.

Aside from cognitive and interpersonal factors, evidence was found that emotional factors are also associated with somatic symptoms in rheumatic diseases. For example, Edwards, Cahalan, Mensing, Smith and Haythornthwaite (2011) state that emotional

processes are crucial contributors to inter-individual differences in the experience of pain in rheumatic diseases. Also, Van Middendorp, Geenen, Sorbi, Van Doornen and Bijlsma (2005a) stress that emotional sensitivity can be a vulnerability factor for psychological distress and perceived symptom severity. However, a study by Van Middendorp et al. (2005b) found emotion regulation not to be directly linked to somatic symptoms. The association between emotion regulation style and perceived health in patients with rheumatoid arthritis was examined. Four dimensions of emotion regulation were found; ambiguity, control, orientation and expression. None of these dimensions was of direct importance to somatic health for rheumatoid arthritis. Yet, it is concluded that emotion regulation may have an indirect link with somatic health through psychosocial well-being.

The above research indicates that multiple factors are associated with pain and fatigue experience in rheumatic diseases. Keefe (1998) notes that these differences stem from how patients perceive their environment and thoughts. This implicates that the severity of the experience of threats will differ due to the way patients perceive a threat. This is consistent with Gilberts' affect regulation theory, which states that threats are different for individuals.

The objective of this study is to identify clusters of threats that rheumatic patients experience to be associated with their symptoms, using the following research question: 'What kind of threats do patients with rheumatic diseases experience?'. First, it will be explored what kind of threat clusters exist for rheumatic patients. It is hypothesized that the perceived severity of threat clusters will differ. It will be explored for each found cluster whether it is experienced by patients as low, medium or high threatening. Based on above literature, it is expected that core threats clusters that will be found are of interpersonal, cognitive or emotional nature. Furthermore, it is expected that an association between the perceived pain and fatigue and the interpersonal, cognitive and emotional threat clusters exists. When it is clear what kind of threats are associated with the experience of pain and

fatigue and to what extent, tools can be developed to help patients manage their threats and as a consequence pain experience may be alleviated.

Methods

Procedure and design

The design of the study was a concept mapping study. The research project consisted of multiple master's thesis studies that focused on threats, soothers or drives. The current study focused on threats. The study consisted of five steps. First, in-depth questions about the threats, soothers and drives were asked in an online survey to collect a broad, diverse set of individual experiences of threats, soothers and drives. Second, a set of statements was derived by the project group from these mentioned threats, soothers and drives. Third, another participant group carried out a card sorting task to organize the statements according to their similarity of meaning. Fourth, a hierarchical cluster analysis was used to structure the outcomes for the threats of the card sorting task. Fifth, patients with a rheumatic disease were selected to investigate how they perceived the found threats (low, medium or high threatening) and which threats were possibly linked to symptom severity. The study was of cross-sectional and observational nature.

Participants

When data collection for the online survey stopped, 724 people had participated. This sample consisted of Dutch (n = 478), English (n = 3), Portuguese (n = 31), Brazilian-Portuguese (n = 117), Greek (n = 50), Spanish (n = 45) speaking participants. Participants had to have a chronic condition and had to be 18 years or older in order to participate. Forty-six of these participants were male (M = 48.67 year, SD = 1.97) and 655 were female (M = 45.12 year, SD = .46). 23 participants did not report their gender.

Prior to the recruitment of participants for the second part of the study, it was investigated how many participants were needed to guarantee the statistical power of the study. Research showed that a sample size between 20 and 30 participants is a good amount of participants for the card sorting task (Wood & Wood, 2008). Previous research showed that the outcome of hierarchical cluster analysis sometimes only stabilizes in between 30 and 60 participants. Only Dutch participants were recruited for the card sorting task. 114 people have participated in the card sorting task.

Measurements

In the online survey, demographics asked were year of birth, gender, country of residence, years of education, civil status, and disease. Participants were asked via an openended question to list as many threats, soothers and drives as possible.

The second part of the study consisted of the card sorting task, a survey asking for basic demographic variables and the Patient Health Questionnaire 15 (PHQ-15) (Kroenke, Spitzer, & Williams, 2002) to assess the somatic symptom severity participants experienced. The PHQ-15 uses a Likert-scale, ranging from 'Not bothered at all', 'Bothered a little', to 'Bothered a lot'. A higher score indicates that the patient experiences more severe somatic symptoms. A score between 0 and 4 was rated as minimal, a score between 5 and 9 as low, a score between 10 and 14 as medium and a score between 15 and 30 as high (Kroenke et al., 2002). The internal reliability of the PHQ-15 is rated as excellent, $\alpha = .80$. The discriminant validity and convergent validity were established (Kroenke et al., 2002). In the current study, the reliability of the PHQ-15 was $\alpha = .717$.

Data collection

Study 1. The first part of the study was an online survey using open questions. The goal of the first part was to assess which threats, soothers and drives patients experienced to be associated with their pain and fatigue experience. Limesurvey was used to build the survey

and collect the data. The online survey (19-219) was approved by the Ethics Committee of the Faculty of Social and Behavioral Sciences of Utrecht University, the Netherlands. All participants gave informed consent.

Recruitment of participants for study 1 was done in the Netherlands, Peru, Brazil, Greece, and Portugal. Participation was anonymous. The survey was available in multiple languages, being Dutch, English, Spanish, Greek, Brazilian-Portuguese and Portuguese. To be assured of a clear, understandable translation of the survey, a forward backward translation procedure was done. The project members translated the survey from English to the other languages. Next, the survey was translated back to English. The survey was also checked by acquaintances of the project members to assure its understandability and clarity. The duration of the survey was 5 till 15 minutes.

The survey was open for responses between October 29th 2019 and November 6th 2019. The survey was posted on multiple websites and in Facebook groups for patients and patient associations. A short text about the survey was posted, accompanied with a picture to draw peoples' attention. People could access the survey by clicking on a link. Participants read the information letter and were asked to give informed consent in order to participate. First, people were asked to answer the demographical questions. Patients were asked to list as many threats, soothers and drives as possible that played a role in their pain and symptom experience. To characterize the participant group, the PHQ-15 was used (Appendix A).

Study 2. The second part of this concept mapping study consisted of a card sorting task. The card sorting task (19-274) was approved by the Ethics Committee of the Faculty of Social and Behavioral Sciences of Utrecht University, the Netherlands.

For the card sorting task, 40 threats, 40 soothers and 40 drives were selected by the project group from the threats, soothers and drives participants mentioned in study 1 following several steps. In the first step, the participants' responses were put into an excel-

sheet and categorized into umbrella categories, such as 'interpersonal problems'. The responses were translated into English. It was counted how many times each response was mentioned to discover if there were overlapping constructs. The project group members made a first selection from these statements to consider to put onto the cards for the card sorting task. This was done in joint consultation by two researchers. The goal was to acquire a diverse set of statements of threats, soothers and drives.

Consensus meetings were held to discuss which statements would be useable for the card sorting task. The selected statements were judged in the consensus meetings on their clarity and understandability for the participants. Four criteria were set to judge the statements; the statement had to be a threat by definition, the statement had to be relevant or usable for the whole group. The threats had to be clear and could not be too abstract or specific. It was attempted to stick close to the original mentioned threat by the participant. Statements that were similar to each other were combined into a more broad one. Statements mentioned by participants that involved multiple threats were split into multiple ones. After the first selection was made, two project group members checked the original items and could file for objection for the made selection. This led to some final changes.

Each specific threat, soother or drive was written in the middle of a card. In the bottom of the card it was written to which category a card belonged. For example, for the cards of the threat category '...is a threat that may cause an experience of harm, danger, damage or unsafety' was written in Dutch. The cards were numbered at random. A final meeting was held in which every project group member had to carry out the card sorting task. It was decided not to use all statements that were put together on the same pile by all the project members because of content overlap.

Participants were recruited between December 13th and December 17th 2019. Recruitment was done via Facebook groups for patients and patient associations in the

Netherlands. When participants wanted to take part in the study, they could sign up via a LimeSurvey link that was posted in the recruitment message. Participants had to give informed consent while signing up via the link.

Participants received an instruction booklet that contained the card sorting instructions and a demographic questionnaire. Participants could write their sorting down in the booklet. The PHQ-15 was included to assess patients' somatic symptoms and their severity (Kroenke, et al., 2002). Participants received an envelope to send back their filled in booklet, and three envelops with 40 cards (for the threats, soothers and drives).

First, participants had to cluster the cards according to similarity of meaning. Participants were asked to organize the cards into minimum 4 and maximum 12 piles. Multiple rules applied to the card organizing; each pile had to be of minimum 2 and maximum 25 statement cards. Statements could only be used once and all judgments had to be classified. Participants had to give a name to each pile they created and fill in the table on the form, writing down the pile names and the numbers of the cards they put on the pile. After this sorting, participants had to do another sorting in which they had to assign the statement to a value, by putting them on piles ranging from pile 1 (least threatening) to pile 5 (most threatening). Participants had to use all the statements and distribute them evenly over the five piles. Participants had to write down the piles they made in a table in the instruction booklet. It was randomized between participants which categories (threats, soothers or drives) they were asked to sort by sending out three different instruction booklets to the participants, in which the order of the instruction for the sorting of threats, soothers and drives differed. After each category, participants were asked to do another card sorting if they still had the energy and motivation to do this. Each sorting took 30 till 45 minutes to complete. The order of instruction was randomized to acquire a similar amount of responses for each category. Participants were asked to return the filled in booklet by post in 10 days.

Data-analysis

For the card sorting task, the data was analyzed using IBM SPSS statistics version 25. The project members entered the number of the pile the participant assigned the card to. The following rules applied when entering the data; if participants did not put a card on any pile, it had to be put on an extra, separate pile. For example, when a participant created seven piles, the card that was not assigned to a pile should be put on pile 8. When a participant put a card on multiple piles, it also had to be put in another separate pile. Next, the average of the two scores had to be calculated and was entered. When participants did not sort according to instruction, notes had to be made in the columns 'Notes_Threat_values', 'Notes_Soother_values', or 'Notes_Driver_values'. Comments of the participants could be noted in the column 'Comments participants'. Scores of participants who did not understand

the task were not entered.

Descriptive statistics was used to analyze the data to describe the participants. Three analyses were carried out. First, hierarchical cluster analysis was used to classify the threats the individuals sorted in the card sorting task. The cells of the input matrix of experiences comprised the number of times that two experiences were not sorted in the same pile. Between each pair of experiences, squared Euclidean distances were computed. To derive the hierarchical structure of experiences, Ward's method was used. The clusters should reflect distinct components of experiences to decide on the number of clusters.

Second, the final number of clusters was chosen. This was guided by the dendrogram and the agglomeration schedule that was produced by the statistical software program showing which experiences are being combined at each stage of the hierarchical clustering process (Klemm, Van Broeckhuysen-Kloth, Van Vliet, Oosterhuis, & Geenen, 2018). Cronbach's Alpha was computed for each cluster to check whether the item scores could be summarized in one cluster score. The reliability scores of the clusters were highest for the

solution with six different clusters. A low Cronbach's Alpha was accepted for some of the clusters, because this was a consequence of the forced ranking in allocating a similar number of threats to each pile.

Third, a repeated measure analysis of variance (General Linear Model) was used to determine the relative importance of the clusters. To examine individual differences and to compare clusters, an analysis of variance and a graphic representation were used. To examine whether an association between a cluster and symptom severity existed, while controlling for covariates, a linear regression was carried out for each cluster.

Results

Participants

Table 1 shows the demographical characteristics of the participant group for the card sorting task; 114 participants took part in the study. Scores from participant 34, 92 and 95 were deleted because they did not understand the task. Participant 94 was deleted because there were no scores. This resulted in 111 participants for analysis. A large part of the participants had a higher educational level (54%). The majority of the participants had a relationship (76%).

Table 1

Descriptive statistics of the participant group for the card sorting task.

Variable	Participant group		
Gender	women	107	
	men	4	
Age	range	22 - 68	
	mean age women	48.41	
	standard deviation women	11.34	
	mean age men	52.50	

	standard deviation men	19.16
Marital status	relationship	84
	no relationship	27
Educational level	lower or middle level	51
	higher level	60
Total		111

Note. Lower or middle educational level was operationalized as elementary school, prevocational secondary education or secondary vocational education. Higher educational level was operationalized as senior general secondary education, pre-university education, higher professional education or university education.

Relationship was operationalized as married, registered partnership, long distance relationship, or living together. No relationship was operationalized as divorced, not living together anymore, or widow(er).

Structure of the threat clusters

To discover which clusters of threats existed in the participant group, a cluster analysis was executed. The resulting dendrogram is shown in Appendix B. The found clusters covered six broad concepts. It was decided to continue with this solution. For cluster 1 'Weather', it was chosen to delete variable 15 'Stimuli such as noises, scents, bright light or radiation'. Deleting this variable heightened the Cronbach's Alpha from $\alpha = .770$ to $\alpha = .804$. It was chosen to delete this variable, to create a more specific cluster. For cluster 2 'Physical factors', variable 8 'Food that is not good for me' and variable 37 'Substance use such as alcohol, cigarettes or soft drugs' were deleted. This heightened the Cronbach Alpha from $\alpha = .512$ to $\alpha = .573$. For cluster 3 'Social pressure and invalidation', it was chosen to delete variable 21 'Getting inadequate care'. Removing this variable heightened the Cronbach's Alpha from $\alpha = .325$ to $\alpha = .551$. For cluster 4 'Limits', variable 5 'Time pressure' was removed. This changed the Cronbach Alpha from $\alpha = .326$ to $\alpha = .408$. The Cronbach Alpha for cluster 5 'Activities' was $\alpha = .687$. The Cronbach Alpha for cluster 6 'Negative feelings' was $\alpha = .690$. No items were deleted in cluster 5 and 6. A schematic representation of the

clusters is shown in figure 1. An overview of the threat names for each item can be found in Appendix A.



Figure 1. Overarching threat clusters and the item numbers belonging to each cluster (the overview of items can be found in Appendix A).

Threat clusters and their relative importance in the patient group

For the patients with a rheumatic disease, it was examined whether the severity of threats for the different clusters differed. For this step, only the data from patients with a rheumatic disease, except patients with fibromyalgia as only diagnosis, was used. This resulted in 49 participants. 47 participants were female (Age: M = 53.30, SD = 8.88), 2 participants were male (Age: M = 53.49, SD = 8.86). Prior to interpreting the results, it was checked if age, gender, education or marital status correlated with the mean scores, using

Pearson's correlation. There were no significant correlations, therefore it was not needed to add covariates into the analysis. Repeated measures analysis of variance (General Linear Model) showed a significant main effect, F(5) = 14.954, p < .001, with a Partial Eta Squared of $\eta_p^2 = .249$. This shows that there is a consistent, large difference between the clusters for patients with a rheumatic disease.

Figure 2 shows the mean participant scores on the clusters. Cluster 2 'Physical factors' and cluster 4 'Limits' had a high mean score. This indicates that patients experience these clusters as more threatening. Cluster 1 'Weather' and cluster 5 'Activities' had a low mean score, which indicates that these clusters are perceived as less threatening by patients. Cluster 3 'Social pressure and invalidation' and cluster 6 'Negative feelings' had a medium mean score. Altogether, this indicates there is a tripartition in the clusters; it differs for the clusters whether they are perceived as low, middle or high threatening.

It was checked whether clusters significantly differed from each other. When clusters significantly differ from each other, it is indicated that they represent distinct threatening clusters and are not overlapping constructs. Table 2 shows the mutual differences between clusters.



Figure 2. Mean (and standard error of measurement) participant scores on threat clusters.

Table 2

Mean scores, standard deviation and mutual differences for each cluster.

Cluster	М	SD	Differs from
Cluster 1 'Weather'	2.62	.18	Cluster 2 and 4
Cluster 2 'Physical factors'	3.40	.08	Cluster 1, 5 and 6
Cluster 3 'Social pressure and invalidation'	3.06	.11	Cluster 4 and 5
Cluster 4 'Limits'	3.65	.10	Cluster 1, 3, 5 and 6
Cluster 5 'Activities'	2.36	.11	Cluster 2, 3 and 4
Cluster 6 'Negative feelings'	2.90	.09	Cluster 2 and 4

Threat clusters and the relationship with the PHQ-15 for the patient group

Using regression analysis, the total PHQ-15 score was correlated with the scores for each cluster to examine whether an association between the threat and symptom severity existed. It was checked whether demographic variables correlated with the PHQ-15 scores.

Age correlated with the PHQ-15 scores, therefore it was added into the regression analysis as a covariate. Cluster 1 'Weather' turned out not to be significantly correlated with the PHQ-15, F(1,42) = 3.997, p = .052. Cluster 2 'Physical factors' did have a significant relationship with the PHQ-15, F(1,43) = 4.534, p = .04. Cluster 3 'Social pressure and invalidation' also was significantly correlated with the PHQ-15, F(1,43) = 4.132, p = .048. Cluster 4 'Limits' proved not to be significantly correlated with the PHQ-15, F(1,43) = 3.513, p = .068. This was also true for cluster 5 'Activities', F(1,43) = .864, p = .358, and cluster 6 'Negative feelings', F(1,43) = 1.891, p = .176. Taken together, these findings show that two threat clusters (cluster 2 and 3) were associated with the experience of somatic symptoms.

Discussion

In current research, it was investigated which threat clusters existed for rheumatic patients and whether these threats were associated with symptom severity. Six clusters of threats were found; 'Weather', 'Physical factors', 'Social pressure and invalidation', 'Limits', 'Activities', and 'Negative feelings'. 'Physical factors' and 'Limits' were experienced as high threatening. In contrast, 'Weather' and 'Activities' were experienced as less threatening by patients. The clusters 'Social pressure and invalidation' and 'Negative feelings' had a medium threat value. Thus, this presumes the existence of a pick order. However, these results are at group level and therefore do not show the individual differences between patients. It was investigated whether clusters were associated with somatic symptom severity. This was the case for 'Physical factors' and 'Social pressure and invalidation'.

It was hypothesized that the clusters would be of interpersonal, cognitive or emotional nature. This was found to be partly true; 'Social pressure and invalidation', 'Limits' and 'Negative feelings' can be classified as of interpersonal, cognitive or emotional nature. Though, 'Weather', 'Physical factors' and 'Activities' cannot be classified using this ranking. This indicates that the current ranking is not comprehensive and that threat clusters of other nature are also of importance.

'Weather' was classified as low threatening by participants, and no association existed with somatic symptom severity. However, multiple studies show that patients often mention weather factors to be associated with their pain experience. For example, Smedslund and Hagen (2011) state that rheumatic patients often claim that their complaints worsen before or during weather changes. Though, their own study was not able to show this relationship.

Furthermore, 'Activities' had a low threat value and was not associated with the pain and fatigue experience of patients. Patients mentioned multiple different activities in study 1. Possibly, some of these specific activities are not experienced as threatening by some participants in study 2, which led to a lower mean threat value for the cluster. Yet, this does not explain why there was no relationship found with symptom experience. Yet, in line with this, Affleck, Tennen, Urrows, and Higgings (1994) also were not able to find a relationship between daily events that were perceived as stressful and pain experience, but they did find a relationship between daily events and mood. This suggests that for rheumatic patients, daily events are not related to pain experience, but may be related to mood, which can be influenced by or stem from daily activities.

Within the cluster 'Physical factors', participants mentioned different factors such as nutrition and sleep. Participants experienced this cluster as high threatening. This does match previous research; for example, Li and Micheletti (2011) point at the positive impact of dietary restriction on rheumatic diseases. For different rheumatic diseases, it was investigated whether dietary restrictions impacted the symptom severity. Especially in gout and osteoarthritis, dietary restriction yielded positive results. Phillips and Clauw (2013) state factors as sleep disturbance and other physical symptoms to be important in pain experience in rheumatic diseases. As mentioned above, participants in current research also mentioned

these factors as threatening. The 'Physical factors' threat factor also has overlap with the symptoms as measured with the PHQ-15 questionnaire. This may have caused the association between the two. Concluding, 'Physical factors' seems to be an overarching factor that is perceived to be associated with symptom severity in rheumatic diseases, although the association might be affected by the overlap with the PHQ-15 questionnaire.

'Social pressure and invalidation' was experienced as moderate threatening and related to symptom severity. This finding is in line with previous research; Kool, Van Middendorp, Lumley, Bijlsma and Geenen (2013) found negative social responses from others related to more health complaints in patients with fibromyalgia or rheumatoid arthritis. In current research, social responses such as expectations and lack of understanding were mentioned by participants as threatening experiences. This fits well to the findings of Kool et al. (2013).

A strength of the current study was that study 1 was carried out in multiple countries and had a large number of participants. Hence, the participant group consisted of participants of different cultures, which may have heightened the diversity of threats found. This variety of threats gave a broad overview of possible factors associated with symptom severity. Another strength of the study was the design of the first part of the card sorting task. In the first sorting, patients were asked to create their own clusters based on the content and assign these clusters a name. This gave a precise representation of how they individually perceived these threats and reflected their personal experience. In the second sorting, participants had to group the cards according to severity and assign all cards to a pile and distribute them evenly. The advantage of this method was that this gave an overview of how severe the participants perceived the threats to be. However, the detriment of this forced ranking was that this could have led to participants putting cards in piles that resembled a threat value (low, middle or high) that did not represent how they actually perceived the threat. This led to low Cronbach Alpha's for the clusters and decreased the reliability. Clusters proved not to be significantly

associated with symptom severity possibly as a consequence of this forced ranking. Also, the participant group in study 2 may have had different characteristics than the rheumatic patient population in society. A big amount of the participants had fibromyalgia comorbid with one or more other rheumatic diseases. This made the participant group of heavy nature, which could have coloured the results. Also, when recruiting participants, over 300 participants initially signed up for the study. One third of these people actually did participate in the study and sent back their results before the university post box was closed due to the corona pandemic. This loss of participants (attrition) may have led to a different sample of participants (Mason, 1999). It is not known whether these participants differed from the other participants, therefore it is not clear whether the sample is an accurate representation of the patient group. The current participant group consisted of a high amount of women (96%). Sloot et al. (2016) state that 61% of patients with rheumatic diseases is female. For patients diagnosed with fibromyalgia, this is 90% (Patient1, n.d.). The mean participant age in the current study was 48.56. The mean age for patients with a rheumatic disease is 68 year (Sloot et al., 2016). The numbers above presumes that the current participant group did not accurately represent the patient group in society. This may have yielded different results.

The current study has generated a ranking of experiences that patients perceive to be threatening. Furthermore, two threatening experiences, 'Physical factors' and 'Social pressure and invalidation', were found to be associated with the experience of symptom severity. This knowledge can be used in clinical practices. A screening instrument can be developed to assess the threats patients experience. This instrument can consist of questions focusing on the six found threat clusters, with an extra emphasize on the clusters with a high threat value and the clusters associated with symptom severity; 'Physical factors', 'Social pressure and invalidation', and 'Limits'. This can be done by asking more in-depth questions regarding these clusters. In therapy, attention can be allocated to the clusters patients indicated as

threatening for them by teaching patients how to manage them. In future research, it should be investigated what self-management tools can be used by patients to manage their threats and whether patients that apply these management techniques experience significantly less impact of these threats.

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Appendix A

Final threats used for the cardsorting study.

- 01) A social activity outside the home 02) Being stressed or tense 03) Holding a certain posture for long 04) Using medication 05) Time pressure 06) An abrupt change in weather 07) A situation that triggers irritation or anger 08) Food that is not good for me 09) Being unable to keep up in a group activity 10) Little time to rest 11) Being physically not active 12) Having worries 13) Poor sleep 14) Memory of a negative past event 15) Stimuli, such as noises, scents, bright lights or radiation 16) Feeling sad or helpless 17) Social pressure and invalidation 18) Getting negative judgments or comments 19) Lack of understanding from others 20) A weather circumstance, such as temperature or humidity 21) Getting inadequate care 22) Physical effort 23) A negative life event 24) Being angry 25) An inflammation, infection, flu or other disease activity 26) Exceeding my limits 27) An argument 28) Having multiple activities scheduled 29) Feeling lonely 30) A task at work or in the household, or an administrative task 31) Doing nothing 32) A negative thought 33) An expectation that I cannot live up to 34) Being out of energy 35) A change in daily routine
- 36) A common physical activity such as walking or cycling
- 37) Substances such as alcohol, cigarettes or soft drugs
- 38) A physical symptom such as pain, fatigue or stiffness
- 39) Getting visitors at home
- 40) Being perfectionistic

Appendix B: Dendrogram



Appendix C: Syntax for the cluster-analysis.

* Encoding: UTF-8.

* FIRST PART OF CLUSTERANALYSIS.SPS.

DATASET DECLARE D0.7933626911670203.

PROXIMITIES T01_outside_social_activity

T02_stressed_tense

T03_posture_for_long

T04_using_medication

T05_time_pressure

T06_Abrupt_change_weather

T07_sit_trig_irrit_anger

T08_food_not_good

T09_unable_keepup_group_activity

T10_little_time_rest

T11_physically_inactive

T12_having_worries

T13_poor_sleep

T14_memory_negative_past_event

T15_stimuli_eg_noise_scents

T16_feeling_sad_helpless

T17_social_pressure

T18_neg_judgments_comments

T19_lack_understanding_others

T20_weather_circumstance

T21_inadequate_care

T22_physical_effort

T23_negative_life_event

T24_being_angry

T25_disease_activity

T26_exceeding_limits

T27_argument

T28_multiple_activities

T29_feeling_lonely T30_task_work_household T31_doing_nothing T32_negative_thought T33_expectation_cannot_liveup T34_out_of_energy T35_change_daily_routine T36_common_physical_activity T37_substance_use T38_physical_symptom T39_getting_visitors T40_being_perfectionistic /MATRIX OUT(D0.7933626911670203) /VIEW=VARIABLE /MEASURE=SEUCLID /PRINT NONE /STANDARDIZE=VARIABLE NONE. *END OF THE FIRST PART OF CLUSTERANALYSIS.SPS.

RECODE T01_outside_social_activity T02_stressed_tense T03_posture_for_long T04_using_medication T05_time_pressure T06_Abrupt_change_weather T07_sit_trig_irrit_anger T08_food_not_good T09_unable_keepup_group_activity T10_little_time_rest T11_physically_inactive T12_having_worries T13_poor_sleep

T14_memory_negative_past_event

T15_stimuli_eg_noise_scents

T16_feeling_sad_helpless

T17_social_pressure

T18_neg_judgments_comments

T19_lack_understanding_others

T20_weather_circumstance

T21_inadequate_care

T22_physical_effort

T23_negative_life_event

T24_being_angry

T25_disease_activity

T26_exceeding_limits

T27_argument

T28_multiple_activities

T29_feeling_lonely

T30_task_work_household

T31_doing_nothing

T32_negative_thought

T33_expectation_cannot_liveup

T34_out_of_energy

T35_change_daily_routine

T36_common_physical_activity

T37_substance_use

T38_physical_symptom

T39_getting_visitors

T40_being_perfectionistic

(2=1)

(4=4)

(6=9)

(8=16)

(10=25)

- (12=36)
- (14=49)
- (16=64)
- (18=81)
- (20=100)
- (22=121)
- (24=144)
- (26=169)
- (28=196)
- (30=225)
- (32=256)
- (34=289)
- (36=324)
- (38=361)
- (40=400)
- (42=441)
- (44=484)
- (46=529)
- (48=566)
- (50=625)
- (52=676)
- (54 = 729)
- (56=784)
- (58 = 841)
- (60=900)
- (62=961)
- (64 = 1024)
- (66=1089)
- (68 = 1156)
- (70=1225)
- (72 = 1296)
- (74 = 1369)

(76 = 1444)

- (78=1521)
- (80=1600)
- (82=1681)
- (84=1764)
- (86=1849)
- (88=1936)
- (90=2025)
- (92=2116)
- (94=2209)
- (96=2304)
- (98=2401)
- (100=2500)
- (102=2601)
- (104=2704)
- (106=2809)
- (108=2916)
- (110=3025)
- (112=3136)
- (114=3249)
- (116=3364)
- (118=3481)
- (120=3600)
- (122=3721)
- (124=3844)
- (126=3969)
- (128=4096)
- (130=4225)
- (132=4356)
- (134=4489)
- (136=4624)
- (138=4761)

(140=4900)

- (142 = 5041)
- (144 = 5184)
- (146 = 5329)
- (148=5476)
- (150 = 5625)
- (152 = 5776)
- (154=5929)
- (156=6084)
- (158=6241)
- (160=6400)
- (162=6561)
- (164=6724)
- (166=6889)
- (168=7056)
- (170=7225)
- (172=7396)
- (174 = 7569)
- (176=7744)
- (178=7921)
- (180 = 8100)
- (182 = 8281)
- (184 = 8464)
- (186 = 8649)
- (188=8836)
- (190=9025)
- (192 = 9216)
- (194=9409)
- (196 = 9604)
- (198 = 9801)
- (200 = 10000)
- (202=10201)

(204 = 10404)

(206 = 10609)

(208 = 10816)

(210=11025)

(212=11236)

- (214 = 11440)
- (216=11664)

(218 = 11881)

(220=12100).

EXECUTE.

*This is the cluster analysis.

CLUSTER

/MATRIX IN(D0.7933626911670203)

/METHOD WARD

/PRINT SCHEDULE CLUSTER(4,12)

/PLOT DENDROGRAM VICICLE.

Dataset Close D0.7933626911670203.

Appendix D: Syntax for the clusters and regressions.

* Encoding: UTF-8.

*For file Gilbert data february 14th.sav.

* GENDER.

* checked, no problems.

*AGE.

* checked, no problems.

* RELATIONSHIP STATUS.

* checked, no problems.

* Relationship status is recoded to having a relationship or not.

RECODE MARITALSTATUS (1=1) (2=2) (3=1) (4=1) INTO RECODED_MARITAL_STATUS.

EXECUTE.

* Variable and value labels should be added in this syntax.

* Moreover, the "other" relationship status should be added.

* The following syntax is suggested.

IF (Marital_Other = "Lat relationship") RECODED_MARITAL_STATUS =2.

IF (Marital_Other = "Lat relationship") RECODED_MARITAL_STATUS =2.

IF (Marital_Other = "lat-relatie") RECODED_MARITAL_STATUS =2.

IF (Marital_Other = "long distance relati") RECODED_MARITAL_STATUS =2.

IF (Marital_Other = "niet samewonend part") RECODED_MARITAL_STATUS =2. EXECUTE.

* Check whether de coding of the last text is okay.

* Is "part" actually "partnership" in the booklet?.

* Discuss whether the "marital_other" RECODES are a good decision.

* EDUCATION.

* checked, no problems.

* Two other education can be used recoded to a given education levelk.

IF (Educ_other = "option 3 and 5") Education=5.

IF (Educ_other = "prop. HBO") Education=5.

EXECUTE.

* RECODE OF EDUCATION INTO LOWER OR MIDDLE VS. HIGHER LEVEL.

RECODE Education (1=1) (2=1) (3=1) (4=1) (5=2) (6=2) (7=2) INTO RECODED_EDUCATION.

EXECUTE.

* Variable and value labels should be added in this syntax.

*DISEASES AND CONDITIONS.

IF (Other_1 = "artritis psoriatica") arthritis_psoriatica=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") SLE_lupus=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") MCTD=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") Sjogren=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") Polyartrose=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") Maag_darm=1.

IF (Other_1 = "poly-artrose, Syndr van gilbert, Sjogren (overlap MCTD SLE)") Gilbert=1.

IF (Other_1 = "Astma") Lung=1.

IF (Other_1 = "Collitis ulcerosa") Maag_darm=1.

IF (Other_1 = "B12 shortage") B12_shortage=1.

IF (Other_1 = "Syndrome from gilber") Gilbert=1.

IF (Other_2 = "Sjögren syndrome") Sjogren=1.

IF (Other_3 = "RLS syndrome") Mobility_disease=1.

IF (Other_1 = "Sjögren") Sjogren=1.

IF (Other_1 = "Tietze") Tietze=1.

IF (Other_1 = "EDS") EDS=1.

IF (Other_1 = "hypermobilitation") Mobility_disease=1.

IF (Other_1 = "Willebrand type 1") Coagulation_diseases=1.

IF (Other_1 = "chronic tendon infla") Pain_body=1.

IF (Other_1 = "acute glaucoma") Eye_diseases=1.

IF (Other_1 = "Sleep apnea") Sleep_apnea=1.

IF (Other_2 = "orestier disease") Forestier=1.

- IF (Other_1 = "sjorgen syndrome") Sjogren=1.
- IF (Other_1 = "sjorgen syndroom") Sjogren=1.
- IF (Other_2 = "Hypermobiel") Mobility_disease=1.
- IF (Other_1 = "ectopic atrial rhyth") Heart=1.
- IF (Other_1 = "langzame schildklier") Thyroid_diseases =1.
- IF (Other_1 = "Ziekte van meniëre") Menieres_disease=1.
- IF (Other_2 = "endometriose") Endometriosis=1.
- IF (Other_1 = "Depressie") Psychiatric=1.
- IF (Other_2 = "autisme-pdd nos") Psychiatric=1.
- IF (Other_1 = "hernia nek") Hernia=1.
- IF (Other_2 = "hernia rug") Hernia=1.
- IF (Other_1 = "FBSS") Pain_body=1.
- IF (Other_1 = "Osteoporose") Osteoporose=1.
- IF (Other_2 = "Scoliose") Scoliose=1.
- IF (Other_1 = "Essentiële trombosy") Cancer=1.
- IF (Other_2 = "hashimoto") Thyroid_diseases=1.
- IF (Other_1= "ADD, sjogren") Psychiatric=1.
- IF (Other_1= "ADD, sjogren") Sjogren=1.
- IF (Other_3= "pernicieuze anemie ") Maag_darm=1.
- IF (Other_2= "longembolie") Lung=1.
- IF (Other_3= "slaapapnue") Slaapapnue=1.
- IF (Other_1= "secondary lymfoedeem") Lymphedema=1.
- IF (Other_1= "endometriosis") Endometriosis=1.
- IF (Other_2= "stolliusziekte") Coagulation_diseases=1.
- IF (Other_3= "lupus anticougulans") Coagulation_diseases =1.
- IF (Other_3= "huidlupus gezicht") SLE_lupus=1.
- IF (Other_1= "ziekte van sjogren") Sjogren=1.
- IF (Other_1= "immundeficientie") Immune_deficiency =1.
- IF (Other_1= "sjogren's disease") Sjogren=1.
- IF (Other_1= "blefaritis") Eye_diseases=1.

EXECUTE.

*WHO DIAGNOSED THE DISEASE?

* checked, no problems.

* selecting specific groups from the data file.

*Run this command to select patients with fibromyalgia.

*Code OF Rheumatic and Musculoskeletal Diseases. IF (Osteoarthritis=1 OR Rheumatoid_arthritis=1 OR Osteoarthritis_2= 1 OR SLE_lupus=1 OR Spondyloartritis=1 OR MCTD=1 OR Sjogren=1 OR Polyartrose=1 OR Osteoporose=1 OR EDS=1 OR Forestier=1 OR arthritis_psoriatica=1 OR Tietze=1 OR EDS=1) RMD=1. EXECUTE.

```
IF (RMD=1) RMD_AND_FM=0.
EXECUTE.
IF (RMD=1 AND FIBROMYALGIA=1) RMD_AND_FM=1.
EXECUTE.
FREQ VAR RMD RMD_AND_FM.
```

*Run this command to select patients with RMD including patients with fibromyalgia. USE ALL. COMPUTE filter_\$=(RMD=1). VARIABLE LABELS filter_\$ 'RMD=1 (FILTER)'. VALUE LABELS filter_\$ 0 'Not Selected' 1 'Selected'. FORMATS filter_\$ (f1.0). FILTER BY filter_\$. EXECUTE.

*PHQ15 SCORES. *calculate them as follows.

COMPUTE TOTAL_PHQ = 15*MEAN.10(PHQ01,PHQ02,PHQ03,PHQ04,PHQ05,PHQ06,PHQ07,PHQ08,

PHQ09,PHQ10,PHQ11,PHQ12,PHQ13,PHQ14,PHQ15).

EXECUTE.

* QUESTION 2.

*1) CHECK FOR ERROS.

*2) COMPUTE CRONBACH ALPHA FOR CATEGORIES TO KNOW WHICH ITEMS SHOULD BE INCLUDED IN THE CALCULATION OF CATEGORY SCORES.

*cronbach alpha categorie 1.

*deleted 15.

RELIABILITY

/VARIABLES=T_value06

T_value20

/SCALE('ALL VARIABLES') ALL

/MODEL=ALPHA

/STATISTICS=CORR

/SUMMARY=TOTAL.

*cronbach alpha categorie 2.

*deleted 37 and 8.

RELIABILITY

/VARIABLES=

T_value04 T_value11 T_value13 T_value03

T_value25 T_value34 T_value38 T_value31

/SCALE('ALL VARIABLES') ALL

/MODEL=ALPHA

/STATISTICS=CORR

/SUMMARY=TOTAL.

*cronbach alpha categorie 3.

*deleted 21. RELIABILITY /VARIABLES=T_value17 T_value33 T_value09 T_value18 T_value19 /SCALE('ALL VARIABLES') ALL /MODEL=ALPHA /STATISTICS=CORR /SUMMARY=TOTAL.

*cronbach alpha categorie 4.

*deleted 5.

RELIABILITY

/VARIABLES=

T_value28 T_value10 T_value26 T_value40

/SCALE('ALL VARIABLES') ALL

/MODEL=ALPHA

/STATISTICS=CORR

/SUMMARY=TOTAL.

*cronbach alpha categorie 5. RELIABILITY /VARIABLES=T_value22 T_value36 T_value30 T_value01 T_value39 T_value35 /SCALE('ALL VARIABLES') ALL /MODEL=ALPHA /STATISTICS=CORR /SUMMARY=TOTAL.

*cronbach alpha categorie 6. RELIABILITY /VARIABLES=T_value24

T_value32 T_value16 T_value02 T_value12 T_value29 T_value07 T_value27 T_value14 T_value23 /SCALE('ALL VARIABLES') ALL /MODEL=ALPHA /STATISTICS=CORR /SUMMARY=TOTAL.

*3) COMPUTE THE (E.G.,) THREAT CATEGORIES.
*categorie 1.
COMPUTE Weather_mean=mean.2(T_Value06, T_value20).
EXECUTE.

*categorie 2.

COMPUTE Physical_factors_mean=mean.5(T_value08 , T_value04 , T_value11, T_value13 , T_value03 , T_value25 , T_value34 , T_value38 , T_value31). EXECUTE.

*categorie 3. COMPUTE Social_pressure_mean=mean.3(T_value17 , T_value33 , T_value09, T_value18 , T_value19). EXECUTE.

*categorie 4.

COMPUTE Limits_mean=mean.3(T_value28, T_value10, T_value26, T_value40). EXECUTE.

*categorie 5.

COMPUTE Activities_mean=mean.4(T_value22, T_value36, T_value30, T_value01, T_value39, T_value35). EXECUTE. *categorie 6.

COMPUTE Negative_feelings_mean=mean.6(T_value24, T_value32, T_value16, T_value02, T_value12, T_value29, T_value07, T_value27, T_value14, T_value23). EXECUTE.

* 4) COMPARE THE MEANS OF THE THREAT CATEGORIES.

* 5) CHECK WHETHER AGE, GENDER OR RECODED_EDUCATION RECODE_MARITAL_STATUS.

* ARE CORRELATED WITH ONE OR MORE OF THE 4 CATEGORIES.

CORRELATE Physical_factors_mean Weather_mean Activities_mean Social_pressure_mean Negative_feelings_mean Limits_mean

WITH age gender recoded_education recoded_marital_status.

EXECUTE.

*geen een correlatie dus geen covariate nodig.

* IF SO, ADD THE COVARIATES IN THE ANALYSIS BELOW.

GLM Weather_mean Physical_factors_mean Social_pressure_mean Limits_mean Activities_mean Negative_feelings_mean

/WSFACTOR=THREATCATEGORIES 6 Polynomial

/METHOD=SSTYPE(3)

/PLOT=PROFILE(THREATCATEGORIES) TYPE=BAR ERRORBAR=SE(2) MEANREFERENCE=NO

/EMMEANS=TABLES(THREATCATEGORIES) COMPARE ADJ(BONFERRONI)

/PRINT=DESCRIPTIVE ETASQ

/CRITERIA=ALPHA(.05)

/WSDESIGN=THREATCATEGORIES.

*QUESTION 3.

* FIRST CHECK WHETHER COVARIATES (THE FOUR) ARE CORRELATED WITH THE DEPENDENT VARIABLE (phq-15).

* iMAGINE : GENDER AND AGE ARE CORRELATE WITH PHQ15.

*THEN INCLUDE THE COVARIATES IN REGRESSION ANALYSIS.

* WE DO THE ANALYSIS SEPRATELY FOR EACH OF THE FOUR CATEGORIES.

* IMAGINE T_value25 IS EXAMINED AS A PREDICTOR OF PHQ15.

*I NEED TO COMPUTE TOTALphq FIRST.

COMPUTE TOTAL_PHQ = 15*MEAN.10(PHQ01,PHQ02,PHQ03,PHQ04,PHQ05,PHQ06,PHQ07,PHQ08,

PHQ09,PHQ10,PHQ11,PHQ12,PHQ13,PHQ14,PHQ15). EXECUTE.

CORRELATE TOTAL_PHQ

WITH age gender recoded_education recoded_marital_status. EXECUTE.

*age is gecorreleerd met total phq. dus toevoegen in de regressie als covariaat.

*VOORBEELD. REGRESSION /MISSING PAIRWISE /STATISTICS COEFF OUTS R ANOVA CHANGE /CRITERIA=PIN(.05) POUT(.10) /NOORIGIN /DEPENDENT TOTAL_PHQ /METHOD=ENTER T_value25 /METHOD=ENTER Gender Age /SCATTERPLOT=(*ZRESID ,*ZPRED).

*regressie voor categorie 1.

REGRESSION

/MISSING PAIRWISE

/STATISTICS COEFF OUTS R ANOVA CHANGE

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT TOTAL_PHQ

/METHOD=ENTER Weather_mean

/METHOD=ENTER Age

/SCATTERPLOT=(*ZRESID,*ZPRED).

*regressie voor categorie 2.

REGRESSION

/MISSING PAIRWISE /STATISTICS COEFF OUTS R ANOVA CHANGE

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT TOTAL_PHQ

/METHOD=ENTER Physical_factors_mean

/METHOD=ENTER Age

/SCATTERPLOT=(*ZRESID,*ZPRED).

*regressie voor categorie 3.

REGRESSION

/MISSING PAIRWISE

/STATISTICS COEFF OUTS R ANOVA CHANGE

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT TOTAL_PHQ

/METHOD=ENTER Social_pressure_mean

/METHOD=ENTER Age

/SCATTERPLOT=(*ZRESID,*ZPRED).

*regressie voor categorie 4.
REGRESSION
/MISSING PAIRWISE
/STATISTICS COEFF OUTS R ANOVA CHANGE
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT TOTAL_PHQ

/METHOD=ENTER Limits_mean /METHOD=ENTER Age /SCATTERPLOT=(*ZRESID ,*ZPRED).

*regressie voor categorie 5.

REGRESSION

/MISSING PAIRWISE /STATISTICS COEFF OUTS R ANOVA CHANGE /CRITERIA=PIN(.05) POUT(.10) /NOORIGIN /DEPENDENT TOTAL_PHQ /METHOD=ENTER Activities_mean /METHOD=ENTER Age

/SCATTERPLOT=(*ZRESID ,*ZPRED).

*regressie voor categorie 6.

REGRESSION

/MISSING PAIRWISE

/STATISTICS COEFF OUTS R ANOVA CHANGE

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT TOTAL_PHQ

/METHOD=ENTER Negative_feelings_mean

/METHOD=ENTER Age

/SCATTERPLOT=(*ZRESID,*ZPRED).