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Comforting factors that influence the severity of fatigue and other somatic symptoms from the perspective of individuals with chronic fatigue syndrome: A concept mapping study

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Preface: Word of thanks

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Abstract

Objective: To broaden the clinical focus beyond suffering in individuals with chronic fatigue syndrome (CFS), it is important to focus on personal sources of strength and resilience in these individuals. The main aim of this study was to identify and examine the underlying hierarchical structure of soothing influences on somatic symptoms from the perspective of individuals with CFS.

Methods: Online interviews yielded a comprehensive overview of 40 soothing influences that were sorted in a card sorting task according to meaning and importance by 73 individuals with chronic somatic symptoms, including seven individuals with CFS. Moreover, the participants completed the PHQ-15 to assess somatic symptom severity. A hierarchical cluster analysis (squared Euclidean distances, Ward's method) was used to obtain the underlying hierarchical structure of soothing influences. The relative importance of each soothing cluster was assessed by a repeated measure analysis of variance, whereas a linear regression analysis was computed to assess associations between soothing clusters and somatic symptom severity.

Results: Hierarchical cluster analysis revealed four overarching categories of soothing influences: '*Social support*', '*Medical Support', 'Adjustment', and 'Self-management'.* These domains comprised 10 clusters. There were no significant differences in the perceived importance of soothing clusters according to seven individuals with CFS, although there was a wide range of individual differences. Adjustment was related to somatic symptom severity, whereas there was no association between social support, medical support, or self-management, and somatic symptom severity.

Conclusions: This study revealed an encompassing hierarchical structure of soothing influences based on individuals with chronic somatic symptoms, including patients with CFS. This structure will guide the development of personalized treatment of individuals with CFS.

1. Introduction

Chronic fatigue syndrome (CFS) is characterized by extreme, medically unexplained, and persistent fatigue for at least six months (Dickson, Knussen, & Flowers, 2008), often in combination with various other symptoms such as impaired memory and muscle pain (Van Middendorp, Geenen, Kuis, Heijnen, & Sinnema, 2001). The impairments that individuals with CFS experience are often severe and enduring (Taylor & Kielhofner, 2005). Whereas the exact cause of CFS remains unknown, there is evidence that physiological and psychological factors play a role. For example, it has been suggested that CFS involves immune system disorders, cardiovascular abnormalities as well as central nervous system disorders (Estévez-López et al., 2018). Besides, it has been revealed that somatoform disorders, which may have some overlap with CFS, involve deficits in affect regulation (Waller & Scheidt, 2004). In accordance, Pinto et al. (2019) propose, based on Gilbert's model of affect regulation (Gilbert, 2016), that fibromyalgia is the result of an imbalance between an overactive threat-detection system and a deficient soothing system. Given the overlap between CFS and fibromyalgia, Gilbert's model (2016), which makes a distinction between three affect regulation systems (threat, drive, and soothing), is considered to better understand and treat CFS as these systems seem to modulate neural activity of somatic symptoms.

The first system is the '*threat and self-protection focused system*' which enables detecting, attending processing, and responding to threat. When the threat system is activated (e.g., social rejection) we experience various negative emotions (e.g., anger, anxiety) thereby promoting defensive actions (e.g., fight, avoidance) (Gilbert, 2016). Whereas activation of the threat system results in the experience of negative affect, there are two different but interactive positive affect regulation systems. One positive affect regulation system is called the '*drive, seeking and acquisition focused system*'. This motivational system is linked to sympathetic arousal with the function of driving behavior to pursue rewards and goals. Activation of this system (e.g., doing things together with friends) leads to the experience of positive, activating emotions including happiness and excitement (Gilbert, 2016). The other positive affect regulation system is called '*contentment, soothing focused system*', which evolved with the attachment system (Gilbert, 2010). When this system is activated (e.g., support), individuals are not threat-focused or seeking resources, but are satisfied (Gilbert, 2016). Activation of this system is linked to prosocial and affiliative behaviors as well as positive deactivating affect states such as social connectedness, safeness, calmness, and wellbeing. Accordingly, this system is linked to parasympathetic arousal and the involvement

of neurohormones such as opiates and oxytocin (Gilbert et al., 2008). In the current study, the term soothing system will be used to improve readability.

Activation of the soothing system is associated with various positive mental and physical health outcomes. To illustrate, safe/content positive affect is negatively related to depression, anxiety, stress, and self-criticism (Gilbert et al., 2008), but positively associated to several processes associated with well-being (Gilbert & Proctor, 2006) and better immune functioning (Kemp & Quintana, 2013). Also, higher levels of positive affect are associated with lower levels of fatigue in pain disorders in women (Zautra, Fasman, Parish, & Davis, 2007). Therefore, helping CFS patients to experience emotions related to soothing system activation may have therapeutic effects (Gilbert et al., 2006). Below, several soothing factors and its overarching categories are proposed based on scientific literature. It is expected that these factors are associated with soothing system activation and subsequent emotions, thereby alleviating CFS symptoms. A look into these resilience factors is important because they provide a menu of (positive) strategies that can help an individual to ameliorate the consequences of CFS (Pinto et al., 2019) and broadens the focus of clinical psychology beyond suffering.

The first category that seems to be related to soothing system activation is social support, including factors such as support and understanding from family and friends (de Lourdes Drachler et al., 2009), and supportive/affiliative interactions with others (Kelly, Zuroff, Leybman, & Gilbert, 2012; Gilbert & Proctor, 2006). To illustrate, Gilbert and Proctor state that affiliation and affiliative interactions have a calming effect, alter pain thresholds and the immune and digestive systems and operate via an oxytocin-opiate system which is in turn associated with feelings of contentment and well-being (Ishak, Kahloon, & Fakhry, 2011). In line with this, higher levels of received social support are related to feelings of social safeness (Kelly, Zuroff, Leybman, & Gilbert, 2012), and parasympathetic nervous system activation (Southwick, 2016). The importance of social support is underlined by findings that indicate that higher levels of social support endorse less distress, less intense pain, and better overall adjustment among pain patients (de Lourdes Drachler et al; Adams & Turk, 2015; Moss-Morris, Petrie, & Weinman, 1996), and higher quality of life among CFS patients (Schoofs, Bambini, Ronning, Bielak, & Woehl., 2004).

Other factors that seem to be related to activation of the soothing system are therapeutic approaches that are often categorized as mind-body therapies (Mehling, et al., 2011), such as compassion-focused therapy, mindfulness, and meditation. To illustrate,

mediation can lead to feelings of peace, calmness, and relaxation (Kabat-Zinn, 2015), which are subsequently related to physiological and psychological benefits (West, 1980). Also, mindfulness, which is centered around increased attentiveness to moment to moment experience, a more open-minded, and a nonjudgmental attitude, is associated feelings of calmness, reduced stress (Monshat et al., 2013). The effect of mindfulness is underlined by evidence reporting that mindfulness-based therapies have a small to moderate positive effect on symptom severity and quality of life in patients with somatization disorders, including CFS (Lakhan & Schofield, 2013). In line with Gilbert's model (2016), affect regulation seems to be one of the mechanisms that explain the soothing effect of mindfulness on somatic symptoms (Hölzel et al., 2011). Finally, soothing/safeness perception can be reinforced by compassion (Pinto et at., 2019) which is the target of compassion-focused therapy (CFT). CFT is directed at facilitating the development of the soothing system by helping people develop and work with experiences of inner warmth and safeness via (self) compassion (Gilbert, 2009). The effect of compassion focused therapy on soothing system activation are confirmed by research showing that compassion focused exercises and imagery stimulate the oxytocin-endorphin system, and increase heart rate variability (Longe et al., 2010; Rockliff, Gilbert, McEwan, Lightman, & Glover, 2008).

Finally, music, which can be categorized under leisure activities (Laukka, 2007), seems to be an important soothing factor. Music has been shown to reduce feelings of stress (Kemper & Danhauer, 2005), hostility, and tension (McCraty et al., 1998), but to increase feelings of relaxation. Besides, music in general (e.g., classical music) has been shown to activate the opioid system (Alparslan et al., 2016; Stefano et al., 2004) and to increase heart rate variability, which are both related to activation of the soothing system (Kemp & Quintana, 2013; Umemura & Hunda, 1998). Although no specific study examined the effects of music on CFS symptoms, music has appeared to be effective for various chronic diseases including osteoarthritis pain (McCaffrey & Freeman, 2003), fibromyalgia (Onieva-Zafra, Castro-Sánchez, Matarán- Peñarrocha, Moreno-Lorenzo, 2013), and osteoarthritis (McCaffrey & Freeman, 2003).

The current project aims to identify relevant soothing factors and to examine the underlying hierarchical structure and relative importance of these factors as perceived by individuals with CFS. Moreover, the aim is to associate these soothing factors with a common level of fatigue and other somatic symptoms. Based on scientific findings, it is hypothesized that patients with CFS experience various soothing factors including support and

understanding from friends and family, supportive/affiliative interactions with others, mindfulness, meditation, compassion-focused therapy, and music which can be subsequently categorized under social support, mind-body therapies and leisure activities, respectively. An encompassing taxonomy of soothing factors can be used in clinical intake to screen for factors that might be relevant targets in therapy for individuals with CFS to mitigate their symptoms.

2. Methods

2.1. Procedure and design

A concept mapping technique, consisting of four steps, was used to quantify qualitative information systematically. First, a group of participants completed an online questionnaire, yielding a comprehensive set of threats, soothers, and drives. The current study will focus on soothers only. Second, a representative set of statements from the questionnaires was selected by the research group. Third, another group of participants sorted the statements according to the similarity of meaning in a card sorting task. They also indicated to which extend the statements influenced their somatic symptoms. Fourth, a hierarchical cluster analysis was used to get a structured overview of soothers unbiased by subjective interpretations of the research group. The study was approved by the Ethics Committee of the Faculty of Social and Behavioural Sciences of Utrecht University (19-219). The study has a cross-sectional and observational design.

2.2. Participants

Participants were individuals with chronic somatic symptoms according to self-report. All participants gave informed consent and had to be 18 years or older. Participants were recruited through internet sites (e.g., Facebook and online homepages) from regional and national patient associations. The research group included seven master's students, including three international students and four Dutch students, and Prof. Dr. Geenen.

2.3. Instruments

All participants completed the PHQ-15 (Kroenke, Spitzer, & Williams, 2002) in their language. The PHQ-15, containing 15 items, was used to assess somatic symptom severity (e.g., stomach pain, dizziness). Participants rated the severity of each symptom during the past 4 weeks on a three-point Likert scale, ranging from 1 (Not bothered at all) to 3 (Bothered a lot). PHQ-15 scores of 5, 10, 15, represent cutoff scores for low, medium, and high somatic symptom severity, respectively (Kroenke et al., 2002). In the current study, a cutoff score of $\geq$10 was used to reflect medium and high somatic symptom severity. The PHQ-15 has been proven to be valid and reliable, with a test-retest reliability of $\alpha = .80$ (Van Ravesteijn et al., 2009).

2.4. Data collection and analyses

2.4.1. Step 1: Online questionnaire

Participants were informed about the general purpose of the study and provided informed consent. Via LimeSurvey, participant's completed an online questionnaire in their language anonymously. This questionnaire assessed demographics, somatic symptoms, and personal threats, soothers, and drives, respectively. These latter three questions were assessed with an open-ended question format. Demographical data included the participant's self-reported gender, nationality, country of residence, age, relationship status, years of education, and (rheumatic) diseases. The online questionnaire took around 5-10 minutes to complete.

2.4.2. Step 2: The selection of soothers

All outcomes were independently screened and selected from the online questionnaire by the research group in several steps. First, the responses regarding the open-ended questions (i.e., threats, soothers, drives) were translated into English. Second, pairs of researchers from the research group categorized the responses on threats, soothers, or drives in groups of overlapping statements. For example, when categorizing soothers, nice weather and warm temperature were put together. Next, subcategories were made within the categories, e.g., a subcategory temperature including heat from the environment and heat from objects. Third, the research group selected representative sets of soothers based on four criteria. First, it had to be a soother by definition. If all researchers agreed that something was not a soother, then it was deleted. Second, it had to apply to the entire group (e.g., soothers that only concerned women or old people were deleted). Third, similar statements were combined and a single

statement involving multiple soothers was split in single ones. Finally, the soother should neither be ambiguous, abstract, or too specific and it had to stick to the original verbalization by the participant as close as possible. In the fourth step, the statements selected by the pairs of researchers were discussed within the research group until consensus was reached about selected outcomes. After that, a few members of the research group read the soothers and made proposals about statements that were wrongly removed. The result was a prefinal set of soothers which was represented by 40 to 48 statements. In the last step, each research member completed the card sorting task to select the final statements. When statements were put on the same pile by each member of the research group and the group agreed that there was considerable overlap, that statement was deleted as it had no differentiating value.

2.4.3. Step 3: sorting by content similarity and perceived importance
Dutch participants were informed about the general purpose of the study via internet sites (e.g., Facebook). After providing informed consent, an instruction booklet including a questionnaire and the card sorting task was sent by post to the homes of the participants. The questionnaire assessed personal characteristics (e.g., gender, age) and the amount and severity of physical symptoms the participant experienced. The card sorting task consisted of three components including threats, soothers and drives which were provided in a different order in the instruction booklet. Each component consisted of two card sorting tasks. In the first card sorting task the following rules applied: all statements had to be placed in a pile; each statement could be placed in one pile only; 4 to 12 piles could be formed, and each pile could contain 1 to 15 statements. The participants sorted statements into piles and gave labels to characterize each pile according to the individual similarity criterion used to sort the statements.

In the second card sorting task participants individually sorted the cards with the statements based on the extent to which they considered them as influences that worsen (i.e., threats) or alleviate (i.e., soothers, drives) their pain, fatigue or other somatic symptoms. The separate statements were rated from 1 (least threatening, soothing, or driving) to 5 (most threatening, soothing, or driving). The following rules applied: statements had to be distributed equally across the five piles, all statements had to be placed in a pile, and each statement could be placed in one pile only. The results were written down on a score form by the participants. To complete all sorting tasks took about two hours and it took about 45 minutes if they did the two sorting tasks of only one component (threats, soothers or drives).

2.4.4. Step 4: hierarchical cluster analysis

Before the data was analyzed the following decisions were made about missing values. First, the sortings of participants who did not understand the task were deleted. Second, occasional cards that have not been put on a pile got a separate pile number. Thus, each card that was not sorted was put on a single pile. Finally, occasional cards that were sorted in two piles, were also put on single piles.

Data were analyzed by using SPSS statistics, version 25. Descriptive statistics were computed. Besides, three analyses were conducted. First, a hierarchical cluster analysis was performed to classify the statements that were individually sorted by the participants during the card sorting task according to their similarity. In cluster analysis, the cells of the input matrix of statements comprised the number of times that two statements were not sorted in the same pile. Squared Euclidean distances were computed between each pair of experiences and Ward's method was used to derive the hierarchical structure of soothers. The main criterion to decide on the number of clusters was that the clusters should reflect distinct components of experiences. The final number of clusters was set by the researchers of the current study, guided by the dendrogram and the agglomeration schedule produced by the statistical software program showing which experiences were being combined at each stage of the hierarchical clustering process [cf. Klemm et al., 2018]. In addition, a top-down interpretation was used starting with two clusters, then three and so on until additional clusters did not yield new content. In the second stage, the contents of both a lower and higher number of clusters were compared to finally decide on the number of clusters, based on the consensus of the research group. The research group gave names to the clusters.

Second, a repeated measure analysis of variance using General Linear Models (GML) was computed to examine the relative importance of each 'soothing' cluster, while controlling for covariates. Individual differences of perceived importance of the 'soothing' clusters were examined by using Box-Jenkins plots. Third, a linear regression analysis was done to assess the associations between the 'soothing' clusters and the severity of somatic symptoms while controlling for covariates. Assumptions were checked.

3. Results

3.1 participants

In total 701 people participated in the online interview. The participants form Europa came from the Netherlands (*n* = 404, Belgium (*n* =51), Cyprus (*n* = 18), Greece (*n* = 30), and Portugal (*n* = 29). The participants from Latin-America came from Brazil (*n* = 109), Peru (*n* =20), and other countries (*n* =40). 73 Dutch participants were included in the card sorting task and the subsequent hierarchical cluster analyses that yielded the dendrogram (organization of clusters). Seven of these participants were diagnosed with chronic fatigue syndrome and reported on average a medium to high somatic symptom severity as measured with the PHQ-15, *M* = 14.83 (9-18). These participants were used in subsequent analyses. Table 1 displays the characteristics of the participants in the interviews and card sorting task.

Table   1

Demographic and clinical characteristics of participants in the interview, hierarchical cluster analysis and card sorting task.

	Interview	**Hierarchical cluster analysis**	**Card sorting**
Sex, n (%)			
Male	46 (6.4%)	4 (5.5%)	1 (14.3%
Female	655 (90.5%)	69 (94.5%)	6 (85.7%)
Mean age in years (min-max)	45.4 (18-80)	49.2 (22-68)	54.1 (48-63)
Relationship status			
Single	113	18	1
Married or living together	453	46	5
Divorced	53	6	1
Widowed	9	-	-
In a relationship	72	-	-
Education level			
Low	247	35	5
High	454	37	2
Diagnoses (rheumatic)			
Osteoarthritis	151	22	3
Fibromyalgia	307	49	7
Rheumatiod arthritis	141	11	-
SLE Lupus	34	2	-
Bechterew's disease	52	-	-
Sjögren syndrome	29	4	-
Psoriatic arhritis	22	-	-

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Scleroderma/systemic sclerosis	30	-	-
MCTD	5	-	-
No rheumatic disease	149	-	-
Diagnoses (non-nheumatic)			
CVS	160	8	7
Job burnout	78	6	1
Irritiable bowel syndrome	267	37	5
Somatofrom disorder	14	1	-
Migraine	159	6	2
Chronic headache	81	3	1
Chronic pain elsewhere in body	252	20	6
Lung disease	112	13	-
Diabetes	44	2	1
Chronic skin condition	66	7	1
Epilepsy	9	-	-
Dementia	5	-	-
Parkinson's disease	1	-	-
Cancer	7	3	-
Cardiovascular diseases	85	7	1
Addiction	55	-	-
Severe obesity	42	9	-
Kidney disease	21	2	-
Psychiatric illness	153	9	1
No non-rheumatic disease	58	-	-
Other chronic disease	294	28	2
Diagnosed by			
Medical specialist	478	67	7
Family physician	42	5	-
Other health care professional	13	-	-
Self-diagnosis	5	-	-

Note. Education: Low = primary education, primary vocational education, secondary general education, secondary vocational education, following 13 or fewer years of education after 6th birthday. High = secondary general education, higher professional education, scientific education, following at least 14 years of education after 6th birthday. SLE = Systemic lupus erythematosus. MCTD = Mixed connective tissue disease. CFS = Chronic fatigue syndrome.

3.2 Dendrogram

The hierarchical cluster solution of which a schematic representation is shown in Fig 1. shows a major distinction of four main categories of soothing influences including social support, adjustment, medical help, and self-management. Three of these categories showed underlying clusters. The underlying clusters of 'social support' included 'intimacy' and 'social

interaction'. The underlying clusters of 'adjustment' included 'rest', 'setting boundaries', 'positivity', and 'safe surroundings'. Finally, 'self-management' consisted of the clusters 'nutrition', 'alternative therapies', and '(physical) activity'. The full dendrogram along with a list of all statements included in the clusters can be found in Appendix A and B.

The solution with 10 clusters was chosen, as increasing the number of clusters to 11 or more was not possible because a single item (25) would form a cluster on their own, while it was a predefined criterion that a cluster should minimally include two soothers. Besides, decreasing the number of clusters from 10 to 9 of less would combine 'intimacy' and 'social interaction' which are considered distinct groups of outcomes. Social interaction is more related to a larger social network, whereas intimacy is more specific to people where a person has a close relationship with.
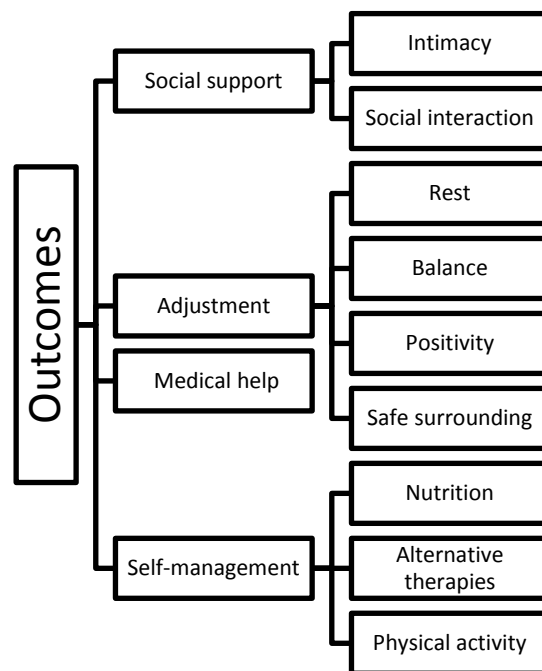

Fig. 1. Schematic representation of the hierarchical structure of perceived soothing influences on somatic symptoms according to individuals with chronic somatic symptoms.

3.3. Perceived importance of soothing influences

In total 12 items (10, 13, 17, 22, 23, 27, 28, 32, 33, 35, 37, 39) were excluded from all subsequent analyses to reach an adequate Cronbach's alpha >.70 in the four soothing categories. As a result, the soothing category 'social support' consisted of 4 items (4, 6,20, 26) and had a Cronbach's alpha score of .78. The soothing category 'adjustment' comprised 12 items (8, 9, 12,15, 16, 24, 25, 27, 30, 31, 34, 36) and had a Cronbach's alpha score of .74. The soothing category 'medical help' contained the original amount of four items (2, 3, 11, 29) and had a Cronbach's alpha score of .75. Finally, the soothing category 'self-management' comprised of nine items (1, 5, 7, 14, 18, 19, 21, 38, 40) and had a Cronbach's alpha score of .72.

Before using the repeated measures analysis of variance, it was checked whether covariates (i.e., gender, age, educational level, marital status) were present. Pearson's correlation indicated that there was not a significant relationship between the soothing categories and gender, age, educational level, or marital status indicating that no covariates were present. Correlations between soothing categories and gender, age, educational level, and marital status are reported in Table 2.

Table 2

Pearson's correlations between soothing categories and gender, age, educational level, and marital status in people with chronic fatigue syndrome

Soothing categories		Gender	Age	Educational level	Marital Status
Social support	Pearson's *r*	.371	.066	-.364	-.575
	p-value	.412	.889	.422	.177
Adjustment	Pearson's *r*	-.387	-.718	-.288	-.666
	p-value	.449	.760	.839	.571
Medical help	Pearson's *r*	.428	-.035	.061	-.405
	p-value	.338	.940	.896	.367
Self-management	Pearson's *r*	-.730	.118	-.132	-.265
	p-value	.100	.825	.803	.612

Note. These analyses were done parametrically with the expectation that the sample size could be extended, which turned out to be not possible before the deadline of the thesis. Therefore, it was decided to do these analyses for didactic purposes in agreement with the supervisor.

Then, several assumptions were checked. Shapiro-Wilk statistics indicated that the assumption of normality was supported in all soothing categories; F_{max} was 2.915, demonstrating homogeneity of variances. Furthermore, Mauchly's test indicated that the assumption of sphericity was not violated.

The results showed that the sample did not significantly perceive some soothing categories as more soothing than others, $F(3, 15) = 1.68$, $p = .214$. Pairwise comparisons showed that there were no significant differences between the means of the soothing categories.

More important than statistics in this small sample size are descriptive analyses. The score distributions of perceived importance of the soothing categories on somatic symptom severity are shown in Fig. 2. The figure shows a wide range of individual differences among participants with CFS. With the exception of two soothing categories (social support and adjustment) the range of the minimum and the maximum score was more than two scores. With this sample size, all soothing categories were –on average– rated about equally important by the participants. However, the soothing category 'adjustment' was experienced as most soothing according to the seven CVS patients. This category included the following soothing influences: 'rest and balance', 'having a positive mindset or mood', and 'being in a calming surrounding'. Concerning to the 40 separate statements, the following influences were experienced as most soothing: 'having the freedom to do something in the way I want to do it myself', 'sleeping', 'understanding my disease', and ' a calm surrounding such as nature, one's own house, pleasurable sound and light'. Appendix C shows the importance scores for the soothing categories, clusters, and the separate statements.
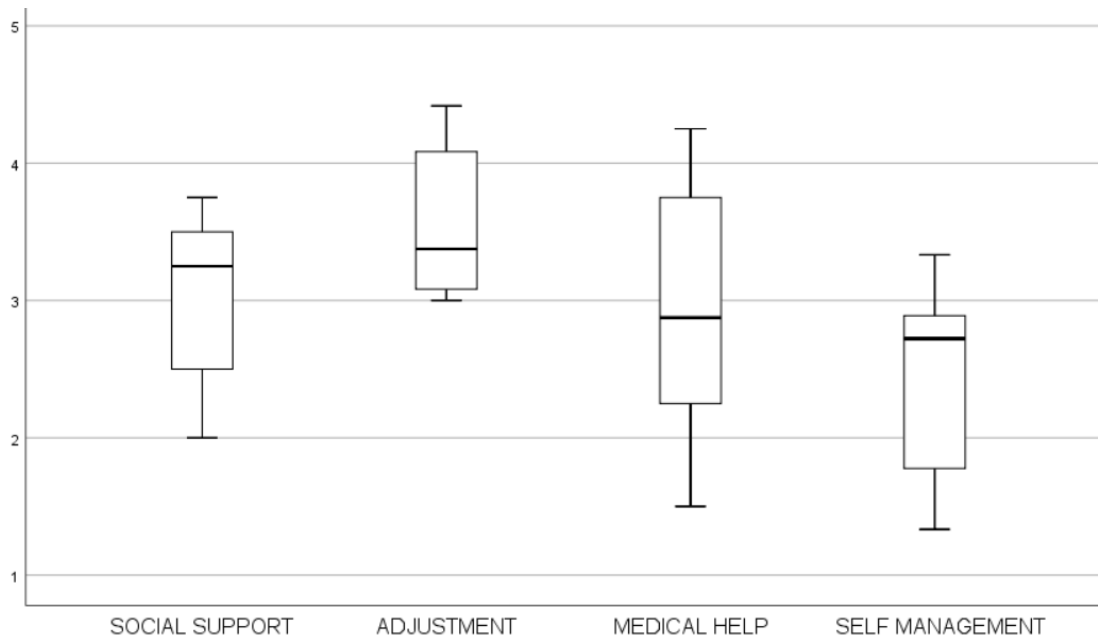
Fig. 2. Boxplot showing the importance of categories as soothing influences on physical symptoms from the perspective of 7 individuals with chronic somatic symptoms. The lowest possible score is 1 (least soothing) and the highest possible score is 5 (most soothing). Each box represents the 25th percentile (bottom of the box) to the 75th percentile (top of the box) with the median in the middle. The bars outside the boxes represent the minimum value and maximum value in the distribution; there were no outliers or extreme scores.

3.4. Association soothing influences and somatic symptom severity (PHQ-15).

To estimate the correlation between social support, adjustment, medical help, self-management, and somatic symptom severity as measured by total PHQ-15 score, a simple linear regression analysis was performed in the seven patients with CFS. Again, although the sample size was too small for the chosen analyses in chronic fatigue syndrome patients, it was decided to do these analyses for didactic purposes in agreement with the supervisor.

Prior to interpreting the results of the regression analysis, it was checked whether covariates (i.e., gender, age, educational level, marital status) were present. Pearson's correlation indicated that there was not a significant relationship between total PHQ-15 score and gender ($r = 0.71$, $p = 0.077$), age ($r = 0.14$, $p = 0.760$), educational level ($r = 0.10$, $p = 0.839$), or marital status ($r = - 0.26$, $p = 0.571$), indicating that no significant covariates were present.

In addition, several assumptions were evaluated. Inspection of the normal probability plot of standardized residuals as well as the scatterplot of standardized residuals against standardized predicted values indicated that the assumptions of normality, linearity, and homoscedasticity of residuals were met.

Linear regression analyses showed that adjustment was significantly and negatively related to physical symptom severity (B = -.40, p = .046). Indicating that considering adjustment important as a soother is related to lower levels of physical symptom severity. With this sample size, neither social support (B = .27, p = .124), nor medical help(B = .14, p = .264), nor self-management were associated with physical symptom severity (B = -.27, p = .116).

4. Discussion

The current study aimed to identify soothing influences and to examine the underlying hierarchical structure in patients with CFS. Moreover, the study aimed to access the relative importance of these influences with regard to the alleviation of somatic symptoms and to access the association between soothing influences and somatic symptom severity in patients with CFS. The study identified an encompassing set of soothing influences from the perspective of 73 individuals with chronic somatic symptoms, including seven patients with CFS. Ten clusters of outcomes were identified that were classified into four broad categories. Three of these categories showed underlying clusters. The first category, social support, comprised the clusters of intimacy and social interaction. The second category, adjustment, comprised the clusters of rest, balance, positivity, and safe surrounding. The third category, self-management comprised three clusters including nutrition, alternative therapies, and physical activity. The fourth category, medical support, had no underlying clusters. These results do relate to the expected categories and are in line with the scientific literature that underlines the soothing effect of mind-body therapies, included in the category 'self-management', social support, and music included in the category 'adjustment' in patients suffering from CFS (Lakhan & Schofield., 2013; Schoofs, Bambini, Ronning, Bielak, & Woehl., 2004).

The soothing categories that were identified in this study seem to relate to a new conceptualization of health which includes not only the physical, emotional, and social health status of people, but also the ability to deal with these future problems (Huber et al., 2011). To

illustrate, patients with CFS seem to manage their symptoms by trying to reduce their symptoms (i.e., medical help), but when symptoms do not change, patients seem to have the ability to adapt and self-manage their symptoms (i.e., adjustment; self-management). This latter finding is in line with a modern view on health and suggests that learning how to deal with symptoms is also a valuable outcome of therapy in patients with CFS (Klemm, Van Broeckhuysen-Kloth, Van Vliet, Oosterhuis, & Geenen, 2018) compared to an outcome measure that only reflects the outcome in symptoms or functioning.

Some authors state that the focus on the positive aspects of functioning has been neglected in previous research (Vazquez, 2017) and now aims to broaden the focus of clinical psychology beyond suffering (Ingram & Snyder, 2006; Lee Duckworth, Steen, & Seligman, 2005). Therefore, the identification of soothing influences is important as it focuses on personal sources of strength and resilience in patients with CFS instead of their vulnerabilities. Moreover, taking into account positive emotions and actions (e.g., calmness, well-being, social connectedness) gives implications for treatment. For example, third-generation therapies including compassion-focused therapy are directed at facilitating the development of the contentment, soothing focused system by among others identifying the client's strengths, positive attributes, or skills. Increasing research shows the value of compassion-focused therapy in clinical populations (Gilbert, 2009).

Concerning the relative importance of the soothing categories (i.e., social support, adjustment, medical help, self-management), the tentative results indicated that, looking at significance, the small sample of individuals with CFS did not perceive some soothing categories as more soothing than others with regard to the alleviation of somatic symptoms. However, the importance attached to these soothing clusters varied a lot between participants. So, what might be perceived as a soothing influence on the severity of somatic symptoms for one person with CFS, might not be perceived as a soothing factor for another person. This finding suggests the importance of portraying what factors a particular patient perceives as soothing. This, in turn, enables therapists to individualize their treatment. This falls in line with patient-centered care that, through personalization is considered to improve treatment motivation, adherence, patient satisfaction, and reduces attrition rates (Evers, Kraaimaat, Van Riel & de Jong, 2002; Olsson, Jakobsson, Swedberg, & Ekman, 2013; Tomba & Fava, 2012).

With regard to the association of soothing clusters and somatic symptom severity, the results showed that in patients with CFS importance ratings on social support, medical support, or self-management were not related to the severity of their somatic symptoms.

The finding that patients rating social support as important was not related to lower levels of somatic symptoms was unexpected. Social support has namely been reported to benefit people with chronic somatic symptoms, including patients with CFS (Adams & Turk, 2015; De Lourdes Drachler et al; Moss-Morris, Petrie, & Weinman, 1996; Schoofs, Bambini, Ronning, Bielak, & Woehl., 2004). The absence of a positive effect on somatic symptom severity in patients rating social support as important might be due to a minimal level of perceived social support. This is in line with research stating that individuals with CFS often report low levels of social support (Lewis, Cooper, & Bennet, 1994). Therefore, this study may reflect a problem typically seen in individuals with CFS (Kelly, Soderlund, Albert, & McGarrahan, 1999).

Interestingly, patients that rated adjustment as important reported a lower level of the severity of their somatic symptoms. This latter finding in combination with research findings showing that patients with chronic illnesses, who learned to cope with their disease and to manage their life better, reported improved self-rated health, less distress, and less fatigue (Lorig et al., 1999), suggests that treatment of CFS might benefit from a focus on strengthening capability to adapt over reduction or elimination of symptoms. The importance of enhancing coping mechanisms among patients with CFS is further confirmed by the disability paradox stating that impaired function does not strongly change perceived quality of life as long as people can develop successful coping strategies (von Faber et al., 2001).

A strength of the current study is that the perspective of patients with chronic somatic symptoms was involved in almost every phase of this concept mapping study. This design allowed a description beyond the subjective interpretation of researchers because patients instead of researches categorized the outcomes in meaningful constructs. As a result, this is the first study that provides an encompassing set of soothing influences from the perspective of patients with chronic somatic symptoms, including patients with CFS.

Nonetheless, the limitations of the study also need to be addressed. First, the main limitation was the lack of power to examine and detect results due to the small sample size which might in part explain the absence of significant effects in patients with CFS. Secondly, the cross-sectional design does not allow causal conclusions. Although the findings suggest that patients with CFS perceiving adjustment important experience a lower severity of somatic symptoms, the shelf life of this conclusion and the possible directions of the association must be further confirmed by future studies.

For example, an experimental design could be used to access whether changes in adjustment cause significant changes in somatic symptom reduction and quality of life in patients with CFS. Thirdly, the sample consisted mainly of women, so without replication, the results of this study cannot be generalized beyond female patients with CFS.

The knowledge of the current study can be used in future research. For example, experimental research could assess whether changes in soothing factors reduce fatigue and improve mood and function especially in patients with CFS that consider this soothing influence important. Besides, it would be interesting for neuroimaging research to clarify the connection between soothing factors, biological substrates (e.g., opiates, oxytocin), and functioning of the contentment, soothing focused system in patients with CFS (Pinto et al., 2019). Furthermore, research should reinforce the available evidence regarding the role of resilience factors and how (im)balances between risk and buffering factors translate into the vulnerability to develop CFS.

With regard to clinical practice, the encompassing taxonomy of soothing clusters can be used in clinical intake to screen for factors that might be relevant targets in therapy for individual patients with CFS in order to mitigate their symptoms. More specifically, the soothing clusters can be used in shared decision making during intake, to define treatment goals, and to map and evaluate change on a personalized set of outcomes. Moreover, the wide variety of soothing clusters and the observation that patients with CFS attach different importance to them motivates the development, testing, and application of new individual outcome measures for effect studies.

Perhaps, psychology has focused more on repairing the negative and neglected the field of promoting the positive. The current study adds to psychological research on positivity by providing an encompassing set of soothing influences in patients with chronic somatic symptoms, including patients with CFS. As a result, the study offers a different and richer perspective on CFS thereby offering promising implications for treatment.

<div align="center">*References*</div>

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Appendix A

The full dendrogram along with a list of all statements resulting from the hierarchical cluster analysis.

Dendrogram using Ward Linkage
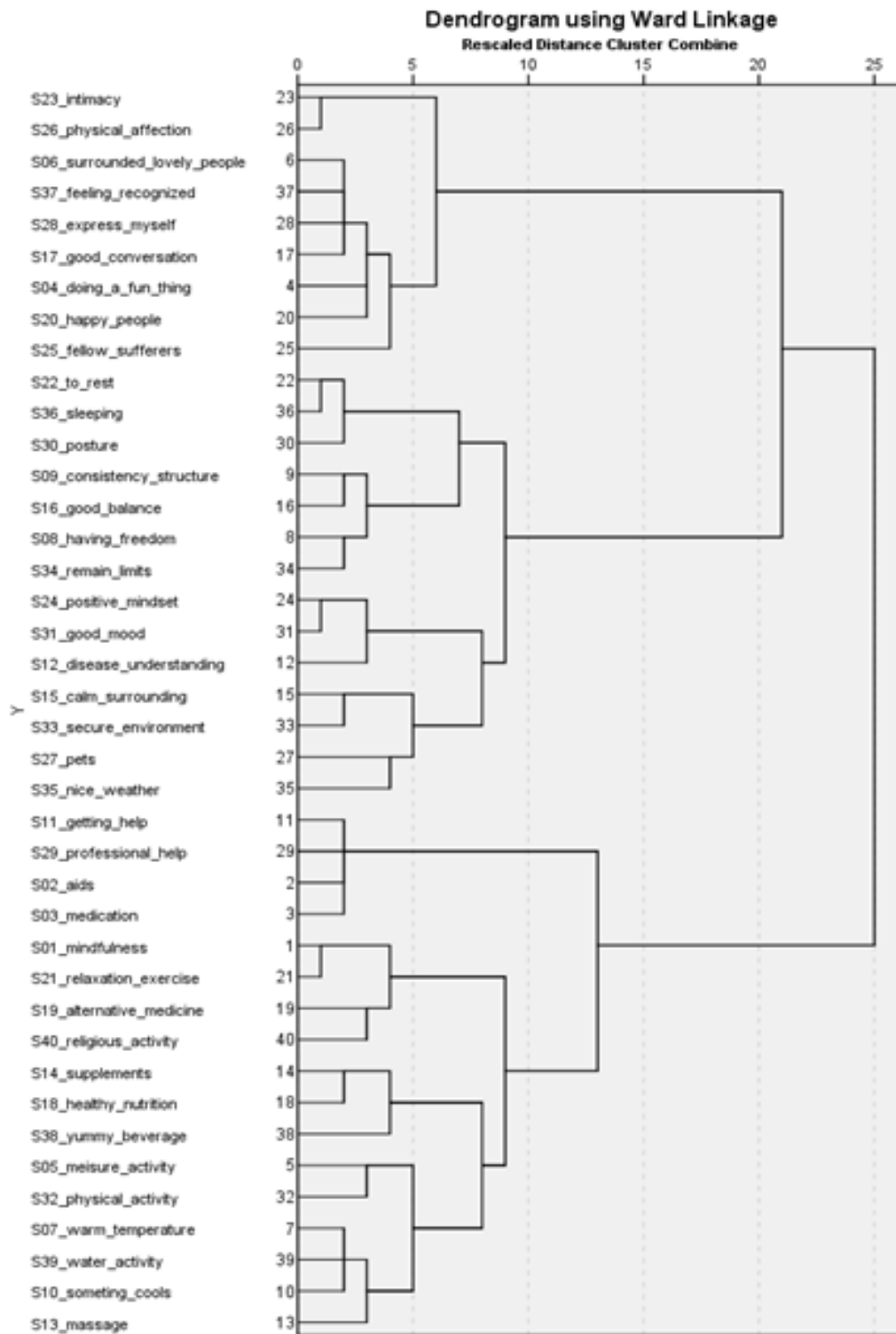
Appendix B

Full name of statements (as received by participants)

[….de kalmeerder…]... is een **kalmerende invloed** die een gevoel van kalmte, welzijn, veiligheid of sociale verbondenheid teweeg kan brengen

1) Mindfulness (in het hier en nu leven en niet veroordelend zijn)
2) Een hulpmiddel (bijvoorbeeld: een rolstoel, kruik, comfortabel matras of goede kussens)
3) Medicatie die ziekteactiviteit of symptomen vermindert
4) Iets leuks doen met familie of vrienden
5) Een vrijtijdsactiviteit, zoals lezen, muziek, film, dansen, tekenen, schilderen of een andere hobby
6) Omringd worden door lieve mensen (bijvoorbeeld vrienden of familie)
7) Warme temperatuur (bijvoorbeeld: bad, infrarood, lamp, warme waterkruik)
8) De vrijheid hebben om iets te doen zoals ik het zelf wil doen
9) Regelmaat en structuur
10) Iets dat me afkoelt (bijvoorbeeld: een koude douche, koude wind, koelgel)
11) Hulp krijgen van andere mensen zoals naasten of specialisten
12) Mijn ziekte of aandoeningen begrijpen
13) Een massage krijgen
14) Supplementen (bijvoorbeeld: vitamines of eiwitten)
15) Een rustige omgeving (bijvoorbeeld: de natuur, het eigen huis, prettig geluid en licht)
16) Een goede balans tussen activiteiten en ontspanning
17) Een goed of positief gesprek voeren
18) Gezonde of goede voeding
19) Een alternatieve geneeswijze (bijvoorbeeld: osteopathie of reiki)
20) Zien dat mensen in mijn omgeving gelukkig en gezond zijn
21) Een ontspannings- of ademhalingsoefening (bijvoorbeeld yoga of meditatie)
22) Rust of een pauze nemen
23) Intimiteit
24) Een positieve instelling hebben (denken, acceptatie, dankbaar zijn)
25) Praten en ervaringen delen met lotgenoten

26) Fysieke genegenheid krijgen (bijvoorbeeld: een streling of een knuffel)

27) Vergezeld worden door huisdieren of zorgen voor huisdieren (bijvoorbeeld honden, katten, paarden)

28) Mezelf uiten naar anderen en weten dat ik er niet alleen voor sta

29) Professionele hulp (bijvoorbeeld van fysiotherapeuten of psychologen)

30) Een comfortabele houding aannemen

31) In een goed humeur zijn

32) Een fysieke activiteit (bijvoorbeeld: wandelen, fietsen, tuinieren, Tai Chi of Qigong)

33) In een veilige en vertrouwde omgeving zijn

34) Binnen mijn eigen grenzen blijven (bijvoorbeeld 'nee' zeggen of om hulp vragen)

35) Mooi weer

36) Slapen

37) Me erkend, begrepen, gerespecteerd, geliefd of belangrijk voelen

38) Een lekkere drank drinken (bijvoorbeeld: thee, cola of een alcoholische drank), een lekkernij eten (bijvoorbeeld: chocolade, snoep) of een sigaret roken.

39) Een activiteit in water (bijvoorbeeld: in het zwembad zijn, drijven in het water, bubbelbad)

40) Een spirituele of religieuze activiteit (bijvoorbeeld: naar de kerk gaan of bidden)

Appendix C

This table shows the mean importance rating (and standard deviation) of each individual item and the overarching cluster of 7 participants with CFS. An example item: '*Intimacy is a soothing factor that may create a feeling of calmness, well-being, safety or social connectedness.* The lowest possible score is 1 (least important) and the highest possible score is 5 (most important). Items with no number regarding mean and standard deviation were excluded from analyses, due to low reliability.

	Importance	
	Mean	**Standard deviation**
CATEGORY: SOCIAL SUPPORT	**3.0**	**0.6**
Cluster 1 – Intimacy	**3.4**	**1.0**
Intimacy (23)		
Receiving physical affection such as being caressed or getting a hug (26)	3.4	1.0
Cluster 2 – Social interaction	**2.6**	**0.5**
Doing a fun thing with family or friends (04)	2.7	0.5
To be surrounded by lovely people (e.g., friends or family) (06)	3.3	0.5
Having a good or positive conversation (17)		
Seeing that people in my environment are happy and healthy (20)	2.4	1.1
Expressing myself to others and knowing that I'm not alone in all of this (28)		
Feeling recognized, understood, respected, loved, liked or important (37)		
Talking to and sharing experiences with fellow sufferers (25)	2.1	0.9
CATEGORY: MEDICAL HELP	**2.8**	**1.0**
Cluster 3 – Medical help	**2.8**	**1.0**
Getting help from other people, such as kins or specialists (11)	3.0	1.4

Professional help (for instance from physical therapists or psychologists (29)	3.1	1.1
Aids (such as a wheelchair, jug, comfortable matrass or good pillows) (02)	2.3	1.1
Medication that reduces disease activity or symptoms (03)	2.7	1.6
CATEGORY: ADJUSTMENT	**3.6**	**0.6**
Cluster 4 – Rest	**3.8**	**1.0**
Take a rest or break (22)		
Sleeping (36)	4.3	1.0
Taking a comfortable posture (30)	3.3	1.3
Cluster 5– Balance	**3.7**	**0.7**
Consistency and structure (9)	3.0	1.7
A good balance between activities and relaxation (16)	2.7	1.5
Having the freedom to do something in the way I want to do it myself (08)	5.0	0.0
To remain within my limits or boundaries (e.g., saying 'no', or asking for help) (34)	3.0	1.5
Cluster 6 – Positivity	**3.8**	**0.5**
Understanding my disease (12)	4.3	0.8
Having a positive mindset (e.g., positive thinking, acceptance, being thankful) (24)	3.8	0.8
Being in a good mood (31)	3.3	1.0
Cluster 7 – Safe surrounding	**4.6**	**0.5**
A calm surrounding such as nature, one's own house, pleasurable sound and light (15)	4.6	0.5
To be in a secure and trusted environment (33)		
Being accompanied by or caring for pets (e.g., horse, dogs, cats) (27)		
Nice weather (35)		
CATEGORY: SELF-MANAGEMENT	2.5	0.9
Cluster 8 – Nutrition	**1.8**	**0.3**
Supplements (vitamins, proteins, and so on) (14)	1.6	0.8
Healthy or good nutrition (18)	2.6	0.8

Drinking a yummy beverage (such as tea, cola or alcoholic drink) ,eating a treat (such as chocolate or sweets) or smoking cigarettes (38)	1.3	0.5
Cluster 9 – Alternative therapies	**2.4**	**1.2**
Mindfulness (living in the here and now and being non-judgmental) (1)	3.1	0.8
A relaxation or breathing exercise such as yoga or meditation (21)	3.0	1.3
An alternative medicine such as oseopathy and reiki (19)	2.1	1.7
Performing a spiritual or religious activity such as going to church or praying (40)	2.0	1.7
Cluster 10 – (physical) Activity	**3.6**	**1.4**
A leisure activity, such as reading, music, movie, dancing, drawing, painting or another hobby (5)	3.6	1.6
Warm temperature (for example, bath, shower, infrared lamp, warm water bag) (7)	3.6	1.3
Something that cools me down (e.g., a cold shower ,cold wind, cooling gels) (10)		
Getting a massage (13)		
A physical activity such as walking or cycling, gardening, Tai Chi or Qigong (32)		
An activity in water (e.g, being in a pool, floating, hot tub) (39)		