

Universiteit Utrecht

Faculty of Social and Behavioural Sciences

Department of Psychology

Master's thesis Clinical Psychology

Drives that may influence the severity of somatic symptoms in inflammatory rheumatic and musculoskeletal diseases: A concept mapping study

Evangelia Anagnostaki

Student No: 6875378

Thesis Supervisor: Rinie Geenen

Word count: 4871

Augustus 2020

Abstract

Introduction: Inflammatory rheumatic and musculoskeletal diseases (IRMD) influence adversely patients' physical and psychological functioning. However, individuals use drives as resilient factors in order to adjust to the context of their disease. The aim of this study was to identify the drives that people with IRMD have and may help them alleviate their symptoms.

Methods: Online questionnaires yielded a comprehensive overview of drives that were sorted in a card sorting task according to similarity of meaning by 53 patients with IRMD (51 female, 2 male; mean age 52.7 (range 27-68) years). Hierarchical cluster analysis (squared Euclidean distances, Ward's method) was used to obtain a structured overview of the drives. Perceived importance of the clusters was examined using repeated measures analysis of variance and the association between the severity of symptoms measured by Patient Health Questionnaire (PHQ-15) scores and the perceived importance of drives using multiple regression analysis.

Results: The hierarchical structure of drives showed 40 drives, classified in four broad categories: *Belonging, Resilience, Personal Development* and *A calm life*. On average, participants perceived *Belonging* as the most important drive and *A calm life* as the least beneficial one. We found no association between the severity of physical symptoms and the perceived importance of drives.

Conclusion: This study offers an encompassing overview of drives that may enhance quality of life and foster the adjustment to the disease. In clinical practice, the clusters of drives can be used as targets of self-management and psychological interventions tailored to treat people with IRMD.

Introduction

Inflammatory rheumatic and musculoskeletal diseases (IRMD), such as rheumatoid arthritis and systemic lupus erythematosus (SLE), have a major and long-lasting effect on the quality of life of patients (van Middendorp & Evers, 2016). Their chronic and progressive nature, accompanied by disabling symptoms of pain, stiffness, and fatigue; their need for long-term medication use with potential serious side effects; and their unpredictable disease course lead to patients requiring to adjust to functional disability, to limitations on almost all areas of daily life (such as work, leisure activities, and social and family life), and to a changed and uncertain future perspective (Overman et al., 2016; Poh et al., 2015; Nikolaus et al., 2013). In addition to the effect of the disease on daily life, the pathophysiological disease process itself, with chronic inflammatory activity, may further influence psychological functioning, for example, due to a direct link between inflammatory processes and depressive symptoms (Rathbun et al., 2013; Lorton et al., 2008).

Literature has shed light on the manner in which patients deal with this chronic stressor that affects their long-term physical and psychological functioning, indicating a number of factors that play a significant role at the adjustment to the disease and the quality of life (Matcham et al., 2014; Strohal et al., 2014; Vriezekolk et al., 2010). One of these factors is emotion and, mostly, emotion regulation, which encompasses the general or situation-specific ways that individuals respond emotionally to stressful events (van Middendorp et al., 2005). In an influential heuristic theory, Gilbert (2010, 2005) suggests that there are three emotion regulation systems that should be considered: the *threat and self-protection system*, the *soothing and contentment system*, and the *incentive and resource-seeking system*. The interaction of these systems reflects the influence of the brain on a person's feelings, urges and desires. The focus of the current study is on the drive system.

In particular, the drive system refers to the positive feelings that guide, motivate and encourage people to pursue and achieve goals and resources in order to survive and prosper (Gilbert, 2010, 2005). This goal-directed motivational behavior is partly regulated by a chemical in our brains called dopamine (Arias-Carrion & Poppel, 2007; Ikemoto & Panksepp, 1999; Berridge & Robinson, 1998). This accomplishment of goals and values relies on motivational systems, such as the sense of belongingness (Baumeister & Leary, 1995) and the care for oneself and for the others (Bowlby, 1969; Wang, 2005). Moreover, the pursuit of personal goals plays a significant role in the psychological adaptation to life with chronic pain (Affleck et al., 1998; Karoly & Ruehlrnan, 1996). Price and Harkins (1992) noted that although chronic pain is initially experienced non reflectively as an intrusion, it may eventually be processed more elaborately in terms of its implications for achieving personal goals. Karoly and Jensen (1987) argued similarly that chronic pain patients can develop *self-defeating schemas* of pain in relation to the accomplishment of cherished goals. The perception of pain-related factors that hinder goal progress can thus be as a critical factor in adapting to life with chronic pain as is the pain itself (Affleck et al., 1998). In particular, a qualitative study (Henriksson, 1995) revealed several common stressors of living with fibromyalgia, including the burden it imposes on achieving personal goals and the difficulty of abandoning their most cherished life plans.

Therefore, the functional and dysfunctional regulation of the drive system in combination with other factors, such as cognitions and behaviours, is the focus of several psychological interventions (van Middendorp & Evers, 2016). In general, the majority of interventions that have been designed to strengthen patients' coping abilities, such as self-management programs and cognitive behavioural therapy (CBT), emphasized improving individuals' cognitive coping skills aiming at goalsetting, problem-solving and modifying negative thoughts (de Ridder et al., 2008; Barlow et al., 2002). Nevertheless, a third generation of approaches is emerging and adds therapies, like Acceptance and Commitment therapy (ACT) (Vowles & Thompson, 2011) and Compassion Focused Therapy (CFT) (Gilbert, 1989, 2005, 2010), to traditional cognitive–behavioural techniques (Roemer & Orsillo, 2010). These new psychological interventions put the importance of pursuit of goals and values at the center of attention.

Hence, the importance of this study lies, firstly, in the fact that in research of adjustment to chronic diseases, including inflammatory rheumatic and musculoskeletal diseases, the main focus has traditionally been on the risk factors for a poor disease outcome, with far less research on resilience factors that prevent a poor outcome (van Middendorp & Evers, 2016). Moreover, the lack of knowledge concerning the theory of the drive system and pursuit of goals in people with IRMD may have a negative impact on the course, action and effectiveness of research. Thus,

trying to minimize the level of psychological burden of patients with IRMD is of high clinical relevance and it will aid the development and refinement of interventions tailored to this patient group. Considering the lack of previous studies in drives in people with rheumatic diseases, an explorative study was conducted. The aim was to examine the drives that people with inflammatory rheumatic diseases have and help them alleviate their symptoms. Therefore, in our study, we examined three research questions. The first question was which drives they have and how these drives are structured in clusters and overarching categories. Secondly, we studied which of the drives are the most beneficial and which of them have the less impact for themselves. Finally, we studied whether and which categories of drives are correlated to the severity of the physical symptoms. Hence, we concluded to three main hypotheses.

Hypotheses:

- We hypothesize that people with IRMD have specific drives that influence the course, the adjustment and the outcome of the disease. Psychological interventions, like Acceptance and Commitment Therapy (Vowles & Thompson, 2011; Vowles et al., 2011; Wicksell et al., 2008) and Compassion Focused Therapy (CFT) (Sirois et al., 2015; Wren et al., 2012) proven to be effective for chronic pain highlight the values of interpersonal relationships, acceptance, self-efficacy and positive feelings as vital drives.
- We hypothesize that the sense of belonging and the emotional support seeking is a considered an important drive as compared to other drives, since it is a interpersonal need which generates positive emotions (Baumeister & Leary, 1995), it enhances the development of self-esteem and self-efficacy (Osterman, 2000) and it helps coping with stress (Bouchard, Guillemette & Landry- Léger, 2004)
- 3. We will examine associations between the severity of symptoms and categories of drives without having specific hypotheses. The severity of physical symptoms in chronic illness and the drive system have similar underlying mechanisms (Gilbert, 2010, 2005; Keefe et al., 2002).

Methods

Procedure

Ethical permission

The two study protocols were approved by the Ethics Committee of the Faculty of Social and Behavioural Sciences of Utrecht University (September 2019, FETC- 19-219 and December 2019, FETC 19-274). Informed consent regarding participation in the study and its purposes was required for inclusion in this study and the responses were saved online anonymously.

Design and data collection

A four step procedure was used in people with inflammatory and musculoskeletal rheumatic diseases. First, a recruitment text was created and distributed via Facebook pages and Internet, accompanied with a link to the information letter, informed consent, and online questionnaire on LimeSurvey. In this online survey, participants were asked to identify the three possible factors which influence somatic symptoms: threats, soothers, and drives. Second, a representative set of statements from the recruitment texts was derived by the research group comprising the supervisor researcher professor and six master's students. This procedure is described in detail by <u>Overgaauw</u> (2020). The research group selected 40 threats, 40 soothers and 40 drives on cards. Third, another group of participants with rheumatic diseases sorted the statements according to similarity of meaning in a card-sorting task. They also put these cards in order of perceived importance of the drives. Fourth, a hierarchical cluster analyses was used to get a structured overview of outcomes unbiased by subjective interpretations of researchers.

For the first part, the data collection was conducted by sending brief recruitment texts to sites of patient associations and posting messages on Facebook pages. The recruitment texts were sent with a link to the information letter, informed consent, and online questionnaire on LimeSurvey. The original text was in English, but I conducted a forward and backward translation in Greek, since the first phase of the study also aimed at Greek participants.

In the card sorting task phase, Dutch participants sorted the threats, soothers and drives derived from the recruitment texts. The task was sent by post to the homes of the patients including an information sheet giving participants the instructions to complete the task. Participants were asked to group cards with threats, soothers and drives according to similarity of meaning on separate piles. The following rules applied: all categories had to be placed in a pile; each statement could be placed in one pile only; each pile could contain 2–25 threats, soothers or drives; and 4–12 piles could be formed. Occasional missing values or items sorted twice were put on separate 1-item "piles", which occurred with 6 participants concerning 9 items in total. The participants were asked to give the piles a label that could be used by the researchers to interpret the sorting. They wrote their sorting threats, soothers and drives on sheets and returned their answers to the researchers by post. In the second task, participants were asked to individually sort the selected threats, soothers and drives into five categories of importance ranging from 'least important' (1) to 'most important' (5) threat, soother and drive. The categories had to be equally allocated to the five categories of importance. This way of prioritizing was used to stimulate participants to think about differences in importance.

Translation

The recruitment text and the online survey aimed at Greek participants. Therefore, a translation of the recruitment text and the online questionnaire, including the information letter, the informed consent and the Patient Health Questionnaire (PHQ-15) was conducted. Translation of the recruitment text and the online survey was performed according to internationally accepted guidelines previously published (Guillemin et al., 1993, Beaton et al., 2000, Wild et al., 2005). The process involves three main steps: a) forward translation, from English to Greek language performed by me. b) backward translation of the final Greek version into English by one English native speaker that was fluent in Greek. At this point, the new English version was compared to the original one and any discrepancies created were resolved by revising the original Greek version. c) Final version of the questionnaire was achieved after backward and forward translations between the revised Greek version and the original English version until no discrepancies were found.

Instruments

In the online survey, participants provided demographic data. They also revealed information concerning the type of rheumatic disease and the person who gave them the diagnosis. Finally, three open questions referring to the threats, soothers and drives were included. Participants also completed the Greek version of the 15-item Patient Health Questionnaire (PHQ-15) (Hyphantis et al., 2014) used for the assessment of the severity of somatic symptoms (Kroenke, Spitzer & Williams, 2002).

Participants

For the first part of the study, the sample consisted of people of the general population with persistent physical symptoms. The recruitment of participants was held by distributing a recruitment text through sites of patient associations and posting messages on Facebook pages. After being informed, signing for informed consent was the only way to open the questionnaire. The only selection criterion was to be 18 and more years old and to experience symptoms of pain, fatigue or other somatic symptoms for a long period of time. Respondents provided demographics (age, gender, education, marital status, and nationality), were asked to specify the type of their rheumatic disease and the person who diagnosed it, and filled out the PHQ-15 questionnaire. Responses were collected anonymously. The final number of the sample was 278 participants.

Data analysis

For the first research question, hierarchical cluster analysis in IBM SPSS statistical software version 24.0 (SPSS) was used to derive the clusters of drives that were individually sorted by the participants during the card sorting task according to similarity of meaning. In cluster analysis, the cells of the input matrix of drives comprised the number of times that two drives were not sorted in the same pile. Squared Euclidean distances were computed between each pair of outcomes and Ward's method was used to derive the hierarchical structure of outcomes. The final number of clusters was set by the members of the project group guided by the dendrogram and the agglomeration schedule produced by the statistical software program showing which statements were being combined at each stage of the

hierarchical clustering process. The main criterion to decide on the number of clusters was that the distinct clusters should reflect groups of drives with a meaning that distinguishes them from other clusters. Thus, the drives that were closest or similar to each other—in terms of Euclidean distance—were sought and grouped in a cluster. The research group gave names to the clusters.

For the second question, Cronbach α was used to test the reliability of each cluster. Moreover, the mean perceived importance was calculated for the distinct clusters and we used descriptive statistics in order to examine the mean of the clusters. Repeated measures analysis of variance using General linear model was also used to compare the clusters.

Finally, for the third research question, in order to test the associations between drives clusters and severity of somatic symptoms derived from PHQ-15 questionnaire, multiple regression analyses were performed. Firstly, we examined the correlation of all drives clusters with PHQ-15 scores and, secondly, each cluster independently. Age was added as a covariate, because it was significantly associated with PHQ-15 scores.

Results

Demographics

The number of participants who agreed to participate in the card sorting task was 111 and 55 of them were people with rheumatic and musculoskeletal disease. Two participants were excluded, because they did not have scores. Therefore, the final number of participants was 53. Information regarding demographic and clinical characteristics is presented per sample in Table 1. The majority of participants in both samples were women.

Table 1

Demographical and clinical characteristics of the participants. The sample of 53 people represents the number of people who conducted the card sorting task and have an inflammatory rheumatic and musculoskeletal diseases.

	Sample with	
	(inflammatory)	
	rheumatic and	
	musculoskeletal	
	disease	
	(<i>n</i> = 53)	
Gender, n (%)		
Female	51 (96.2%)	
Male	2 (3.8%)	
Mean age in years (min-max), SD	52.7 (27-68), 9.1	
Civil status		
Married or partnership	39	
Single	5	
Divorced	6	
Other	3	
Education		
Higher education	26	

Middle/lower education	23	
Diagnosis		
Osteoarthritis	33	
Fibromyalgia	33	
Rheumatoid arthritis	11	
Osteoarthritis2	11	
Systemic lupus erythematosus	2	
(SLE)	2	
Chronic fatigue syndrome /	7	
Myalgic encephalomyelitis	/	
Burn out	-	
Irritable bowel syndrome	30	
Somatoform	-	
Migraine	7	
Headache	2	
Body pain	15	
Lung	8	
Diabetes	6	
Skin	12	
Cancer	4	
Heart	3	
Obesity	9	
Kidney	2	
Psychiatric	6	
Other	40	
Diagnosed by		
Specialist	52	
Family physician	1	
Health professional	-	
Mean years since diagnosis (min-	13 0 (1 47)	
max)	(SD) 12.0	
	(52) 12.0	

Card sorting task

A list of 40 drives was derived from the online survey. The number of sorted piles varied from four to seven across the participants. A dendrogram with the outcome of hierarchical cluster analyses is shown in Appendix. The solution with four clusters was chosen in order to reach an acceptable value for the Cronbach's α of the perceived importance of items within each cluster and, so, each cluster reflects the meaning of the drives.

So, according to a schematic representation of the dendrogram with the outcome of hierarchical cluster analyses shown in Fig. 1, the drive categories are divided into four broad clusters: the first cluster *Belonging*, referring to social support and the importance of being part of a group, the second cluster *Resilience*, referring to positive emotions as coping mechanism, the third cluster *Personal development*, referring to alterations in quality of life, and the fourth cluster *A calm life*, referring to the relaxed way of life that people with IRMD wish to have. Cronbach's alpha was used to test the reliability of each cluster. These coefficients are much lower than, for instance, the Cronbach's alpha obtained in questionnaires due to the forced sorting procedure. The reliability coefficient should be close to .6 in order to have a high enough internal consistency. However, according to Field (2014), Cronbach's alpha close to .5 is also sufficient. For the first cluster, $\alpha = .55$, for the second cluster $\alpha = .60$, for the third cluster $\alpha = .56$ and for the fourth cluster $\alpha = .57$.



Fig. 1. Schematic representation of the hierarchical structure of drive clusters. The content of the items was abbreviated.

Perceived importance

Repeated measures analysis of variance (GLM) showed a significant main effect for the difference between categories. The partial eta squared reflected a large effect size (*partial* $\eta^2 = .55$, F = 18.7) (Cohen, 1988 as cited in Ellis, 2010). Posthoc analyses showed that the first cluster of *Belonging* was the most important drive (M = 3.65, SD = .90), followed by the third cluster, *Personal development* (M = 3.35, SD = .57) and the second cluster *Resilience* (M = 3.44, SD = .83). The fourth cluster of *A calm life* was measured as the least important drive (M = 2.39, SD = .78). Fig. 2 shows the mean values of the perceived importance of clusters. The fourth cluster differs from the other three clusters and the error variance of cluster 4 does not overlap with any other variance (p < .05). The standard deviations show that there were considerable individual differences between the importance attached to the four drive clusters.



Fig. 2. The mean importance of drives as perceived by participants (with standard error of measurement). The lowest possible score is 1 (least important) and the highest possible score is 5 (most important).

Drives and the severity of physical symptoms

A multiple regression analysis was performed to assess the association between the severity of physical symptoms measured with PHQ-15 and the drive categories. We also computed the correlation between the PHQ scores and three demographic variables: age, gender and education. We found a significant association only between age and PHQ scores (p < .05) and, for this reason, age was used as a covariate at the final regression analyses.

According to the results presented in table 2, two models were identified. In the first model, age was not added as covariate, whereas in the second one, age was included. In model one, we found no significant association between the drive categories and the PHQ-15 scores [F (4, 42) = 0.20, p = .94]. However, there was a significant association between the PHQ-15 scores and age, when the latter was added as a covariate [F (1, 41) = 4.42, p = .42], since people in a younger age experience a deterioration of physical symptoms. The results of multiple regression analysis are presented in table 2.

Finally, regression analyses were conducted to measure the association between the scores derived from the PHQ-15 and each drive category independently. We did not find any association between the two variables in model one, whereas, in model two, there was a significant correlation after controlling for the age. Thus, according to our results, *Belonging* [F (1, 44) = 4.12, p = .05], *Resilience* [F (1, 44) = 4.45, p = .04], *Personal development* [F (1, 44) = 4.51, p = .04] and *A calm life* [F (1, 44) = 4.24, p = .05].

Table 2. Regression analyses of the association between the severity of somatic symptoms and drives without (Model 1) and with (Model 2) age included.

Severity of somatic symptoms (PHQ-15)

Drives	h	Standard	ß	4	Sia
Model 1	D	Error (s.e.)	þ	l	Sig
Belonging	.455	.806	.090	.564	.575
Resilience	456	1.337	057	341	.735
Personal	436	.899	079	485	.630
Development					
A calm life	.085	.992	.015	.086	.932
Model 2	b	Standard Error (s.e.)	β	t	Sig
Belonging	.250	.781	.049	.320	.750
Resilience	923	1.305	116	707	.483
Personal development	698	.874	127	799	.429
A calm life	.355	.976	061	363	.718
Age	165	.078	320	-2.102	.042*

* *p* < .05.

Discussion

Individuals with inflammatory rheumatic and musculoskeletal diseases (IRMD) face a variety of daily and ongoing stressors, including pain and functional limitations, which require coping strategies in order to enhance their quality of life and alleviate their physical symptoms (Gignac, Cott, & Badley, 2000). The aim of the current study was to examine the drives that people with IRMD have as resilient factors. Forty drives were identified and they were classified in four broad categories including *Belonging, Resilience, Personal development* and *A calm life*. Living a clam life was considered the least important drive. Individual differences regarding preferred drives were large.

In general, according to classical theories of stress and coping, functional disability caused by IRMD may pose a stressor that requires the initiation of coping actions (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). The successful activation of drives could be a key element of adjustment to living with IRMD. Our study adds to previous theories (Affleck et al., 1998; Karoly & Ruehlrnan, 1996) by offering a comprehensive overview of forty specific drives stemmed from an online survey among people with persistent physical symptoms. The drives were organized in four broader clusters. The first cluster, *Belonging*, includes drives like *being understood* and be loved, underlying the sense of belongingness, supported by Baumeister and Leary's (1995) belongingness hypothesis. According to the hypothesis, human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships. This interpersonal need has such a strong motivational power, since it generates positive emotions, such as joy, bliss and love (Baumeister & Leary, 1995). We labeled the second cluster *Resilience*, as it consists of drives like *think positive, accept myself* and *be happy*. It refers to emotions and cognitive appraisals that people with IRMD have as a motivation of adjustment to the disease (van Middendorp & Evers, 2016). The third cluster named as Personal development, indicates the need of people with IRMD to achieve a better quality of life and their personal autonomy, since the disease causes a decline in their quality of life (Woolf & Xeger, 2003). Finally, A calm life reflects the creation of peaceful conditions in life and the absence of intense physical activity, since the latter is a source of discomfort (Dupond, 2011). Individuals with IRMD experience excessive

energy expenditure, deficient energy production, or inadequate recovery (Dupond, 2011).

Concerning the second research question, we found that the ratings of the importance within the clusters showed large individual differences and *Belonging* was selected as the most important drive. This drive comprises not only the sense of belongingness, but also the quality of social support and emotional support by significant others (Matcham et al., 2015). Our findings are consistent with previous research supporting the value of belongingness and social support in IRMD. Good quality social support has shown to protect against psychological distress and increase in physical symptoms (Sturgeon et al., 2016; Geenen et al., 2012; Walker et al., 1999). It has also been shown that problematic, unwanted, or stressful relationships lead to increased distress, higher symptom levels, and increased inflammatory activity in rheumatic diseases, thus indicating that the quality of social support is particularly important (Sturgeon et al., 2016; Matcham et al., 2015; Nikolaus et al., 2013). Nevertheless, there is mixed evidence regarding whether emotional support seeking is associated with better or poorer adjustment in individuals with chronic illness (McCombie et al., 2013; Pellissier et al., 2010; Schussler, 1992).

Resilience and *personal development* had a similar score that does not diverge significantly from the first cluster. In general, acceptance and self-efficacy have been shown to generally protect against psychological distress and increase in physical symptoms (Sturgeon et al, 2016; Geenen et al., 2012; Walker et al., 1999). Positive emotions seem to buffer the relationship between pain and negative emotions (Strand et al., 2006) and are associated with decreased pain intensity, measured over subsequent days or weeks (Zautra, Johnson & Davis, 2005). Individuals who report being optimistic or accepting of their pain show increased resilience to pain, and are less likely (than pessimistic and non-accepting patients) to have high levels of physical dysfunction in the early stages of the disease (Pinto-Gouveia, Costa & Marôco, 2015; Treharne et al., 2005). Similarly, feelings of self-efficacy and confidence in one's ability to manage ongoing physical symptoms are predictive of reduced pain, increased goal achievement, and improved quality of life (Knittle et al., 2011).

Finally, living a calm and relaxing life was the drive that got the least priority and the difference in importance with the other three drives was significant. This finding deviates from a previous body of evidence showing that resting and sleep act usually as revitalizing components of physical symptoms, like fatigue (Dupond, 2011). In general, fatigue is a frequent constitutional symptom reported by patients with IRMD (Overman et al., 2016) that reduces physical performance and it is partly attributed to an abnormality of sleep physiology (Mahowald & Mahowald, 2000). It is also induced by muscle activity that is relieved by resting the affected muscle(s) (Mahowald & Mahowald, 2000). McCracken & Iverson (2002) also suggested that disrupted sleep and rest predict impaired daily functioning and physical symptoms independent of pain that is one of the pivotal physical symptoms.

As for the third research question, we did not find an association between the drives and the severity of physical symptoms. This finding is not consistent with the previous literature, according to which, the severity of physical symptoms in chronic illness and the drive system have similar underlying mechanisms. The biopsychosocial model provides a systems perspective on the mechanisms underlying the severity of physical symptoms. The model suggests that the pain and disability experienced by people having IRMD is not only affected by underlying biological factors, but also by psychological and social factors (Keefe et al., 2002). Similarly, the drive system is a part of Gilbert's model of affect regulation (Gilbert, 2010, 2005), according to which, all individuals, independently to their condition, are fundamentally driven towards basic biopsychosocial goals and motives (e.g., defense, resource-seeking, affiliation) that are crucial to accomplish the ultimate goals of any living organism: survival and reproductive success. The fact that a relationship was not found in the current study is perhaps fully explained by the forced sorting procedure in which participants had to sort the 40 cards across five piles. Thus, even someone who is very motivated by all drives had to put many cards on the less important piles and a person without drives still had to indicate which drives were the most important.

Since our study breaks new ground in the indication of resilient factors that may alleviate physical symptoms, its implications for clinical practice are significant. Previous literature documented the efficacy of the third generation approaches for people with IRMD, by identifying the resilient factors, identical to the drives that we found, by focusing on inner motivational systems towards the accomplishment of a cherished goal (van Middendorp & Evers, 2016). These interventions have contributed to an amelioration of symptoms, psychological well-being, and daytime functioning complaints by reducing the stress reaction. For instance, Acceptance and Commitment Therapy (ACT) (Vowles & Thompson, 2011; Vowles et al., 2011; Wicksell et al., 2008) and Compassion Focused Therapy (CFT) (Sirois et al., 2015; Wren et al., 2012) can foster adaptive responses to the perceived setbacks and shortcomings that people experience in the context of living with a chronic illness. Thus, our findings could help to recommend treatment strategies that are designed to signify the value of achievement of desired goals and the content of specific goals. A few limitations of this study should be noted. Firstly, only part of the people approached enrolled in the study, which probably reflects a selection bias in the direction of highly motivated individuals. Nevertheless, 53 participants were left for main analysis, which is enough in this kind of analyses. Another limitation is that we measured mostly the physical symptoms by distributing the PHQ-15 questionnaire and, hence, the evaluation of psychological symptoms was not taken into consideration.

In conclusion, in this study, the value of personal drives in psychological adaptation to life with IRMD has been comprehensively described. Our findings shed light on the theory of the drive system and pursuit of goals in people with IRMD by giving an overview of and supporting the existence of specific drives included in four broad categories. Despite some limitations, our study contributes to the growing awareness of the resilient factors as the main focus of psychological interventions. Nonetheless, a strong need remains for a comprehensive integrative framework to foster and guide research and development of much needed effective interventions. Further research may focus on incorporating the drives into personalized interventions and measuring the treatment outcome and, so, potentially modify the chronic illness experience.

Reference list

Affleck, G., Tennen, H., Urrows, S., Higgins, P., Abeles, M., Hall, C., Karoly, P., & Newton, C. (1998). Fibromyalgia and women's pursuit of personal goals: A daily process analysis. *Health Psychology*, *17*(1), 40–47. <u>https://doi-org.proxy.library.uu.nl/10.1037/0278-6133.17.1.40</u>

Arias-Carrión, Ó., & Pöppel, E. (2007). Dopamine, learning, and reward-seeking behavior. *Acta Neurobiologiae Experimentalis*, 67(4), 481–488.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Selfmanagement approaches for people with chronic conditions: a review. *Patient Educ Couns*, 48, 177–87. https://doi.org/10.1016/S0738-3991(02)00032-0

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin*, *117*, 497–529. doi:10.1037/0033-2909.117.3.497.

Beaton, C., Bombardier, F., Guillemin, F., & Ferraz, M.B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25* (24), 3186-3191. DOI: 10.1097/00007632-200012150-00014.

Bouchard, G., Guillemette, A., & Landry-Leger, N. (2004). Situational and dispositional coping: An examination of their relation to personality, cognitive appraisals, and psychological distress. *European Journal of Personality*, *18*, 221–238. <u>https://doi-org.proxy.library.uu.nl/10.1002/per.512</u>.

Bowlby, J. (1969). Attachment: Attachment and loss. London: Hogarth Press.

Berridge, K.C., & Robinson, T.E. (1998). What is the role of dopamine in reward: hedonic impact, reward learning, or incentive salience?. *Brain research*, *28*(3), 309-369. https://doi.org/10.1016/S0165-0173(98)00019-8

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2nd ed.). New York: Academic Press.

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, *372*(9634), 246-255. doi: 10.1016/s0140-6736(08)61078-8

Dupond, J. (2011). Fatigue in patients with rheumatic diseases. *Joint Bone Spine*, 78, 156-160. <u>https://doi.org/10.1016/j.jbspin.2010.05.002</u>

Field, A. (2014). Discovering Statistics Using IBM SPSS Statistics. And Sex and Drugs and Rock'n'Roll. *Pflege*, *27*(6), 430-430. doi: 10.1024/1012-5302/a000397.

Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, *55*, 745–774. doi:10.1146/annurev.psych.55.090902.141456

Geenen, R., Newman, S., Bossema, E., Vriezekolk, J., & Boelen, P. (2012). Psychological interventions for patients with rheumatic diseases and anxiety or depression. *Best Practice & Research Clinical Rheumatology*, *26*(3), 305-319. https://doi.org/10.1016/j.berh.2012.05.004.

Gignac, M. A. M., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55, 362–372. <u>https://doi-org.proxy.library.uu.nl/10.1093/geronb/55.6.P362</u>

Gilbert, P. (2010). Compassion focused therapy. Hove: Routledge.

Gilbert P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy*. New York, NY, US: Routledge.

Gilbert, P. (1989). *Human nature and suffering*. Hove, UK: Lawrence Erlbaum Associates.

Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaption of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, *46*, 1417-1432. <u>https://doi.org/10.1016/0895-4356(93)90142-N</u>

Henriksson, C. (1995). Living with Continuous Muscular Pain-Patient Perspectives. *Scandinavian Journal Of Caring Sciences*, *9*(2), 77-86. doi: 10.1111/j.1471-6712.1995.tb00391.x

Hyphantis, T., Kroenke, K., Papatheodorou, E., Paika, V., Theocharopoulos, N., & Ninou, A. et al. (2014). Validity of the Greek version of the PHQ 15-item Somatic Symptom Severity Scale in patients with chronic medical conditions and correlations with emergency department use and illness perceptions. *Comprehensive Psychiatry*, 55(8), 1950-1959. doi: 10.1016/j.comppsych.2014.08.042

Ikemoto, S., & Panksepp, J. (1999). The role of nucleus accumbens dopamine in motivated behavior: a unifying interpretation with special reference to reward-seeking. *Brain research*, *31*(1), 6-41. <u>https://doi.org/10.1016/S0165-0173(99)00023-</u>5.

Keefe, F. J., Smith, S. J., Buffington, A. L. H., Gibson, J., Studts, J. L., & Caldwell, D. S. (2002). Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. *Journal of Consulting and Clinical Psychology*, *70*(3), 640–655. https://doi-org.proxy.library.uu.nl/10.1037/0022-006X.70.3.640

Karoly, P., & Ruehlman, L. (1996). Motivational implications of pain: Chronicity, psychological distress, and work goal construal in a national sample of adults. *Health Psychology*, *15*, 383-390. doi: 10.1037//0278-6133.15.5.383

Karoly, P., & Jensen, M. (1987). *Multimethod assessment of chronic pain*. New York: Pergamon Press.

Knittle, K., De Gucht, V., Hurkmans, E., Vlieland, T., Peeters, A., Ronday, H., & Maes, S. (2011). Effect of self-efficacy and physical activity goal achievement on arthritis pain and quality of life in patients with rheumatoid arthritis. *Arthritis Care & Research*, *63*(11), 1613-1619. doi: 10.1002/acr.20587

Kroenke, K., Spitzer, R., & Williams, J. (2002). The PHQ-15: Validity of a New Measure for Evaluating the Severity of Somatic Symptoms. *Psychosomatic Medicine*, *64*(2), 258-266. doi: 10.1097/00006842-200203000-00008

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.

Lorton, D., Lubahn, C., Zautra, A., & Bellinger, D. (2008). Proinflammatory Cytokines and Sickness Behavior in Rheumatic Diseases. *Current Pharmaceutical Design, 14*(13), 1242-1260. doi: 10.2174/138161208799316375 Matcham, F., Ali, S., Hotopf, M., & Chalder, T. (2015). Psychological correlates of fatigue in rheumatoid arthritis: A systematic review. *Clinical Psychology Review*, *39*, 16-29. doi: 10.1016/j.cpr.2015.03.004

Matcham, F., Scott, I., Rayner, L., Hotopf, M., Kingsley, G., & Norton, S. et al. (2014). The impact of rheumatoid arthritis on quality-of-life assessed using the SF-36: A systematic review and meta-analysis. *Seminars In Arthritis And Rheumatism*, 44(2), 123-130. doi: 10.1016/j.semarthrit.2014.05.001

Mahowald, M., & Mahowald, M. (2000). Nighttime sleep and daytime functioning (sleepiness and fatigue) in well-defined chronic rheumatic diseases. *Sleep Medicine*, *1*(3), 179-193. doi: 10.1016/s1389-9457(00)00029-0

McCombie, A. M., Mulder, R. T., & Gearry, R. B. (2013). How IBD patients cope with IBD: A systematic review. *Journal of Crohn's and Colitis*, *7*, 89 – 106. https://doi-org.proxy.library.uu.nl/10.1016/j.crohns.2012.05.021

McCracken, L. M. (1998). Learning to live with the pain: acceptance of pain predicts adjustment in persons with chronic pain. *Pain* 74 (1), 21-7. https://doi.org/10.1016/S0304-3959(97)00146-2

Nikolaus, S., Bode, C., Taal, E., & van de Laar, M. (2013). Fatigue and Factors Related to Fatigue in Rheumatoid Arthritis: A Systematic Review. *Arthritis Care & Research*, 65(7), 1128-1146. doi: 10.1002/acr.21949.

Osterman, K.F. (2000). Students's need for belonging in the school community. *Review of Educational Research*, *70*, 323-367. <u>https://doi-</u>org.proxy.library.uu.nl/10.3102/00346543070003323.

Overgaauw, E. (2020). 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. Utrecht: Master's thesis Utrecht University.

Overman, C., Kool, M., Da Silva, J., & Geenen, R. (2015). The prevalence of severe fatigue in rheumatic diseases: an international study. *Clinical Rheumatology*, *35*(2), 409-415. doi: 10.1007/s10067-015-3035-6.

Pellissier, S., Dantzer, C., Canini, F., Mathieu, N., & Bonaz, B. (2010). Psychological adjustment and autonomic disturbances in inflammatory bowel diseases and irritable bowel syndrome. *Psychoneuroendocrinology*, *35*, 653–662. https://doi.org/10.1016/j.psyneuen.2009.10.004

Pinto-Gouveia, J., Costa, J., & Marôco, J. (2015). The first 2 years of rheumatoid arthritis: The influence of acceptance on pain, physical limitation and depression. *J Health Psychol.*, *20*, 102–112. <u>https://doi-</u>org.proxy.library.uu.nl/10.1177/1359105313499807

Poh, L., He, H., Lee, C., Cheung, P., & Chan, W. (2015). An integrative review of experiences of patients with rheumatoid arthritis. *International Nursing Review*, 62(2), 231-247. doi: 10.1111/inr.12166

Price, D., & Harkins, S. (1992). Psychophysiological approaches to pain measurement and assessment. In D. Turk & R. Melzack (Eds.), *Handbook of pain assessment* (pp. 111-134). New York: Guilford Press.

Rathbun, A.M., Reed, G. W., & Harrold, L.R. (2013). The temporal relationship between depression and rheumatoid arthritis disease activity, treatment persistence and response: a systematic review. *Rheumatology*, *52*, 1785-94. <u>https://doi-org.proxy.library.uu.nl/10.1093/rheumatology/kes356</u>

Roemer, L., & Orsillo, S.M. (2010). *Mindfulness- and Acceptance-Based Behavioral Therapies in Practice*. New York: The Guildford Press.

Schussler, G. (1992). Coping strategies and individual meanings of illness. *Social Science and Medicine*, *34*, 427–432. <u>https://doi.org/10.1016/0277-9536(92)90303-8</u>

Sirois, F.M., Molnar, D. S., & Hirsch, J. K. (2015). Self- Compassion, Stress, and Coping in the Context of Chronic Illness. *Self and Identity*, *14* (3), 334-347, <u>https://doi.org/10.1080/15298868.2014.996249</u>

Strand, E., Zautra, A., Thoresen, M., Ødegård, S., Uhlig, T., & Finset, A. (2006). Positive affect as a factor of resilience in the pain—negative affect relationship in patients with rheumatoid arthritis. *Journal Of Psychosomatic Research*, *60*(5), 477-484. doi: 10.1016/j.jpsychores.2005.08.010. Strohal, R., Kirby, B., & Puig, L. (2013). Psoriasis beyond the skin: an expert group consensus on the management of psoriatic arthritis and common co-morbidities in patients with moderate-to-severe psoriasis. *Journal Of The European Academy Of Dermatology And Venereology*, 28(12), 1661-1669. doi: 10.1111/jdv.12350.

Sturgeon, J., Finan, P. & Zautra, A. (2016). Affective disturbance in rheumatoid arthritis: psychological and disease-related pathways. *Nat Rev Rheumatol*, *12*, 532–542. <u>https://doi-org.proxy.library.uu.nl/10.1038/nrrheum.2016.112</u>

Treharne, G.J., Kitas, G.D., Lyons, A.C., & Booth, D.A. (2005). Well-being in rheumatoid arthritis: the effects of disease duration and psychosocial factors. *J Health Psychol.*, *10*, 457–474. https://doi-

org.proxy.library.uu.nl/10.1177/1359105305051416

Van Middendorp, H., &. Evers, A. (2016). The role of psychological factors in inflammatory rheumatic diseases: From burden to tailored treatment. *Best Practice & Research Clinical Rheumatology*, *30*, 932-945. https://doi.org/10.1016/j.berh.2016.10.012.

van Middendorp, H., Geenen, R., Sorbi, M., Hox, J., Vingerhoets, A., van Doornen, L., & Bijlsma, J. (2005). Gender Differences in Emotion Regulation and Relationships with Perceived Health in Patients with Rheumatoid Arthritis. *Women & Health*, 42(1), 75-97. doi: 10.1300/j013v42n01_05.

Vowles, K. E., McCracken, L.M, & O'Brien, J. Z. (2011). Acceptance and valuesbased action in chronic pain: A three-year follow-up analysis of treatment effectiveness and process. *Behaviour Research and Therapy*, *49*, 748-755. <u>https://doi.org/10.1016/j.brat.2011.08.002</u>

Vowles, K. E. & Thompson, M. (2011). Acceptance and commitment therapy for chronic pain. In L. M. McCracken (Ed.). *Mindfulness and Acceptance in Behavioral Medicine: Current Theory and Practice* (pp. 31-60).

https://www.newharbinger.com/mindfulness-and-acceptance-behavioral-medicine

Vriezekolk, J., Eijsbouts, A., Evers, A., Stenger, A., Van Den Hoogen, F., & van Lankveld, W. (2009). Poor psychological health status among patients with inflammatory rheumatic diseases and osteoarthritis in multidisciplinary rehabilitation: Need for a routine psychological assessment. *Disability And Rehabilitation*, 32(10), 836-844. doi: 10.3109/09638280903323250

Walker, J. G., Littlejohn, G. O., McMurray, N. E., Cutolo, M., (1999). Stress system response and rheumatoid arthritis: a multilevel approach. *Rheumatology*, *38* (11), 1050–1057, <u>https://doi-org.proxy.library.uu.nl/10.1093/rheumatology/38.11.1050</u>

Wang, S. (2005). A conceptual framework for integrating research related to the physiology of compassion and the wisdom of Buddhist teachings. In P. Gilbert (Ed.), *Compassion: Conceptualisations, research and use in psychotherapy* (pp. 75–120). London, UK: Routledge.

Wicksell, R. K., Ahlqvist, J., Bring, A., Melin, L., & Olsson, G. L. (2008). Can exposure and acceptance strategies improve functioning and life satisfaction in people with chronic pain and whiplash-associated disorders (WAD)? A randomized controlled trial. *Cognitive Behaviour Therapy*, *37*,169-182. <u>https://doi-org.proxy.library.uu.nl/10.1080/16506070802078970</u>

Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., Erikson, P. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: reports of the ISPOR task force for translation and cultural adaptation. *Value Health*, 8 (2), 94-104. https://doi.org/10.1111/j.1524-4733.2005.04054.x

Woolf, A.D., & Xeger, B. (2003). Burden of major musculoskeletal conditions. *Bulletin of the World Health Organization*, *81*, 646–656.

Wren, A., Somers, T., Wright, M., Goetz, M., Leary, M., & Fras, A. et al. (2012).
Self-Compassion in Patients With Persistent Musculoskeletal Pain: Relationship of
Self-Compassion to Adjustment to Persistent Pain. *Journal Of Pain And Symptom Management*, 43(4), 759-770. doi: 10.1016/j.jpainsymman.2011.04.014

Zautra, A.J., Johnson, L.M., & Davis, M.C. (2005). Positive affect as a source of resilience for women in chronic pain. *J Consult Clin Psychol.*, 73, 212–20. doi: 10.1037/0022-006X.73.2.212.

Appendix



Figure. Dendrogram showing the sorting of drive variables

The dendrogram shows the cluster solution. The X axis represents the stage of hierarchies which enables the identification and classification of clusters. The Y axis presents the number and the meaning of each item.