Masterthesis

The Relation of Resilience and Resilience-Related Factors with Fatigue in Rheumatic Patients

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Abstract

Background: Rheumatic disorders are common and have far reaching consequences. Among others, fatigue is a symptom from which patients suffer substantially. But fatigue is largely ignored in treatment decisions. One possible way to target fatigue in the treatment of rheumatic patients might be through resilience. The positive effects of resilience and related factors such as positive affect, acceptance and engaged living are well established in pain research. The relations of resilience and related factors with fatigue is less studied. The present study aims at investigating these relations.
Method: Patients from the 'Reumacentrum Twente' were invited by (postal) mail to participate in the survey. The survey consists of questions about demographics, fatigue (Vitality scale of the SF-36), resilience (BRS and RSnl), acceptance (AAQ-II), positive affect (Positive Affect scale of the PANAS), engaged living (ELS) and pain (VAS). 57 respondents were taken into analyses. Correlation-, regression- and mediation analyses were conducted.
Results: Resilience, fatigue, pain, acceptance, positive affect and engaged living were associated with each other. In a multivariate model, resilience and positive affect were related to fatigue. Mediating effects were found for positive affect in the relation between resilience and fatigue. There was full mediation by positive affect when resilience was assessed as personality trait and partial mediation when resilience was assessed as ability. The relation between positive affect and resilience remained when pain was taken into account only for resilience assessed as ability. No significant relations of acceptance and engaged living were found with fatigue in the multivariate model.
Discussion: Definitions and operationalizations of resilience have a wide variation, narrowing these would facilitate resilience research. Both resilience as trait and as ability seem to be important to fatigue. The mediating effect of positive affect underlines the importance of promoting positive affect in the face of adversity. Including fatigue in treatment decisions and target it through resilience and positive affect might have beneficial effects for rheumatic patients.

1. Introduction

The aim of the present study is to gain more insight into the relation between resilience and fatigue and factors that might be important in this relation among patients that suffer from rheumatism.

About 25% of the population suffer from a rheumatic disease (Deutsche Gesellschaft für Rheumatologie e.V., 2012). The prevalence of rheumatic diseases rises with age (Falsarella et al., 2012). Females are more often affected between the ages of 20 – 50, then men are affected as often as women (Falsarella et al., 2012; Downe-Wamboldt & Melanson, 1998). Due to a higher life expectancy the prevalence of rheumatic diseases is increasing worldwide (Falsarella et al., 2012; Johnston et al., 2015).

The causes of rheumatic diseases are not well discovered yet but many factors have been identified to play a role in the development of a rheumatic disease (Astin et al., 2002). Sunar et al. (2015) mention different immune, neuroendocrine and psychosocial variables and Bode & Taal (2015) add environmental, hormonal and reproductive factors in relation with a genetic disposition which are meant to influence the development of a rheumatic disease.

There are more than 100 rheumatic diseases. Common rheumatic diseases are rheumatoid arthritis [RA], ankylosing spondylitis [AS], osteoarthritis [OA] and fibromyalgia [FM]. According to the National Institutes of Health [NIH] (2014) common symptoms of these diseases are “inflammation (signs include redness or heat, swelling, and symptoms such as pain) and loss of function of one or more connecting or supporting structures of the body. They especially affect joints, tendons, ligaments, bones, and muscles. Common signs and symptoms are pain, swelling, and stiffness.“. Pain and discomfort often come in repeated episodes that are hard to predict and control (Zautra et al., 2001). Moreover, a common symptom in rheumatic diseases is fatigue (Evers et al., 2011).

Rheumatic diseases have a considerable negative impact on both physical and mental health (Falsarella et al., 2012). There is no known cure for rheumatic diseases (Downe-Wamboldt & Melanson, 1998), but in the last 20 years treatment options improved profoundly (Stoffer et al., 2016; Östlund et al., 2016). Most treatments target remission or low-disease

activity and lead to less disability, reduced symptoms such as pain and improvements in physical functioning (Stoffer et al., 2016; Östlund et al., 2016; Astin et al., 2002; Bode & Taal, 2015). Despite this great advancement in treatment, many patients still suffer daily from rheumatic symptoms such as pain and fatigue (Flurey et al., 2014).

In contrast to pain, fatigue receives little attention in treatment decisions, although fatigue is perceived as severe as pain (Mayoux-Benhamou, 2006; Hewlett et al., 2011). Repping-Wuts et al. (2008) even state that half of RA patients experience fatigue as more bothersome than pain and according to Mayoux-Benhamou (2006) 57% of RA patients reported fatigue as most problematic symptom of their disease. Furthermore, fatigue is, besides pain, the most common symptom in RA (Repping-Wuts et al., 2008). It is reported by 88 – 98% of rheumatic patients (Novaes et al., 2011). The level of fatigue can be high even in well-controlled RA populations (Repping-Wuts et al., 2008). According to patient reports, fatigue is characterized by tiredness, exhaustion, weakness, lack of energy and a decreased capacity for physical and mental work (Novaes et al., 2011; Mayoux-Benhamou, 2006). They experience incapacity to produce muscle strength and feelings of dejection, somnolence and irritability (Schneeberger et al., 2015). Fatigue varies in duration and intensity and is perceived as uncontrollable and overwhelming (Repping-Wuts et al., 2008; Hewlett et al., 2011).

The quality of life [QoL] of patients with fatigue is significantly reduced and fatigue was identified to be the best measurement (i.e. better than pain) to distinguish between RA patients who are doing well and those who are doing less well concerning QoL (Schneeberger et al., 2015; Mayoux-Benhamou, 2006). The negative impact of fatigue is not restricted to physical aspects such as sleep disturbance and high rates of hospitalization and mortality but also affects cognitive/emotional functioning, such as depression, psychological distress, mental-health related QoL, satisfaction with health, feelings of frustration and attitudes, and social/environmental aspects such as work ability, negative and positive daily events, parenting, social participation, role functioning, relationships, leisure time and everyday tasks (Mayoux-Benhamou, 2006; Falsarella et al., 2012; Nikolaus et al., 2013; Repping-Wuts et al., 2008; Bode & Taal, 2015). The far reaching consequences make fatigue a priority for patients, but fatigue is largely ignored by clinicians (Hewlett et al., 2011; Mayoux-Benhamou, 2006).

Little attention has been paid to the nature of RA-related fatigue (Mayoux-Benhamou, 2006). The phenomenon fatigue is not well understood and the etiology is unknown (Nikolaus et al., 2013; Repping-Wuts et al., 2008). Causes of fatigue seem to be multidimensional and there seem to be differences between individuals (Hewlett et al., 2011).

Assessing individual differences in terms of affect, behavior and cognitions may create more insight in the phenomenon of fatigue in rheumatic diseases and its determinants which might reveal new possible treatment approaches for fatigue (Anderson et al., 1985). For a long time, the field of psychological research was restricted to psychopathological factors which distinguished only sick individuals from healthy ones. More recently, the research focus has shifted from psychopathology to positive psychological constructs that have a beneficial effect on the individual (Davydov et al., 2010). The availability of resources for helping individuals with chronic diseases to develop more positive psychological functioning is scarce (Hamilton et al., 2006). The assessment of the ability to recover may be more important than the assessment of the ability to resist illness when studying people who are already ill (Smith et al., 2008).

The ability to recover from stress is one definition of resilience (Smith et al., 2008). But there is no universally accepted definition of resilience as it involves many factors, has been developed in diverse disciplines and is a new study field (Cabanyes Truffino, 2010). Resilience entails a reduced vulnerability to adverse events, the overcoming of adversity, and good functioning despite adversity (Rutter, 2006). There is an ongoing discussion whether resilience is a stable personality trait that is genetically determined, a dynamic process involving learning or even a mixture of these (Portzki et al., 2010; Slepian et al., 2016). According to both approaches, exposure to adversity, as which a rheumatic disease can be considered, is necessary to show resilience (Friborg et al., 2006; Johnston et al., 2015). On the one hand, regarding resilience as a personality trait, resilience entails predispositional characteristics that facilitate overcoming adversity (Resnick & Inguito, 2011). On the other hand, resilience can be conceptualized as the ability to bounce back or recover from stress (Smith et al., 2008). This ability might be developed through learning (Slepian et al., 2016). It is important to find the underlying mechanisms through which resilience promotes its beneficial effects (Cabanyes Truffino, 2010). In the physically ill, a range of variables was

associated with resilience (Johnston et al., 2015) among which positive affect, acceptance and engaged living.

Several studies have found a positive relationship between resilience and positive affect (Slepian et al., 2016; McAllister et al., 2013). Positive affect seems to be an important resilience factor (Strand et al., 2006; Resnick & Inguito, 2011). The resilient effect of positive affect is among others highlighted in the 'broaden-and-build' theory of positive emotions. According to this theory, RA patients who experience more positive affect have a greater capacity to recover physiologically and psychologically from stressful events (Strand et al., 2006). Often, positive affect is seen as a resource that helps individuals to adapt during times of stress and might serve as buffer or protect against negative effects (Zautra et al., 2001). Zautra et al. (1995) found that positive affect could serve as a measure of the impact of chronic illnesses like RA. Positive affect is associated with favorable health outcomes and with overcoming undesirable experiences (Dockray & Steptoe, 2010; Haddadi & Besharat, 2010). High positive affect embodies pleasurable engagement with the environment and feelings of enthusiasm, alertness, activity, interest, joy, determination and high energy; low positive affect comprises lethargy, sadness and fatigue (Pettit et al., 2001). Positive affect is independent from and more than just the opposite of negative affect (Zautra et al., 1995).

Another construct related to resilience is acceptance. Ramirez-Maestre & Esteve (2014) stated that resilience and acceptance are interconnected and that resilience contains measures of acceptance. This statement is supported by Evers et al. (2011) who identified acceptance as a resilience cognition and Resnick & Inguito (2011) who labeled acceptance a characteristic of resilience. With regard to chronic illnesses as RA, acceptance means adaptation while being able to tolerate the unpredictable and uncontrollable nature of the disease and cope with its averse consequences (Evers et al., 2001). It does not mean to surrender, to the contrary, it is an active attitude (Ramirez-Maestre & Esteve, 2014). It is a flexible and efficient attitude that applies to thoughts, emotions and adverse life events (Ruiz-Párraga & López-Martínez, 2015; Hamilton et al., 2006). RA patients with an accepting attitude adapted better to the disease and suffered less from disease-related discomfort and were less likely to develop depression (Cepuch et al., 2014; Pinto-Gouveia et al., 2015). Acceptance serves as an adaptive function for the long-term psychological and physical health

of the chronic ill, without the need to control the disease (Evers et al., 2001).

Knowing and living according to own values describes the concept of engaged living (Trompetter et al., 2013) and has been proposed as a resilience factor (Froh et al., 2010). Engaged living indicates the recognition and knowledge of personal values and undertaking goal-directed actions according to these values and the evaluation of this (Trompetter et al., 2013). Resilient individuals are more likely to engage in valued activities (Ruiz-Párraga & López-Martínez, 2015) and being able to structure goals is characteristic of resilience (Karoly & Ruehlman, 2006). The concept of engaged living is already used in the Acceptance and Commitment Therapy [ACT] and there known as engaged response style (Trompetter et al., 2013). It might help RA patients to struggle less with the disease and to live in the here and now (Pinto-Gouveia et al., 2015). Less use of the health-care system, less distress and less disability are some of the benefits of engaged living (Pinto-Gouveia et al., 2015).

Resilience, positive affect, acceptance and engaged living have received little attention in research of fatigue related to a rheumatic disease. More research has been done with regard to pain among rheumatic patients. Brionez et al. (2010) discovered that only 13% of the variance in pain can be explained by RA severity and that an additional 41% of the variance was predicted by psychological factors. Conner et al. (2006) highlight the importance to examine these factors. Among these factors, resilience was found to be a better predictor of pain and physical functioning in OA patients than disease severity (Stewart & Yuen, 2011). Resilient patients reported less pain (Friborg et al., 2006). Positive affect was identified as a form of resilience to deal with negative pain-related outcomes (Froh et al., 2010) and resilience seems to enhance positive affect (Haddadi & Besharat, 2010). Experiencing positive emotions despite pain predicted lower pain intensity (Slepian et al., 2016). Pain intensity was also negatively related to acceptance (Trompetter et al., 2015). Engaged living was negatively correlated with pain disability and pain interference (Trompetter et al., 2013).

The aim of this study is to investigate the relation of resilience and acceptance, positive affect and engaged living with fatigue. Smith et al. (2008) found a negative relation between resilience and fatigue. In this study, a negative relation between fatigue and resilience is expected. Evidence that acceptance, positive affect and engaged living are not only linked to resilience but also to fatigue has already been found. Acceptance was found to be

negatively correlated with fatigue in RA patients (Repping-Wuts et al., 2008). Less accepting RA patients reported higher levels of fatigue (Nikolaus et al., 2013). Presumably, there is a negative relationship between fatigue and acceptance. Davis et al. (2011) found an association between fatigue and positive affect. High levels of fatigue were present in RA patients with low positive affect (Pettit et al., 2001). Therefore, a negative relationship between fatigue and positive affect is assumed. Difficulties to live an engaged life were associated with fatigue (Bode & Taal, 2015). A negative relationship between fatigue and engaged living is expected.

It is important to study the influence that positive affect, acceptance and engaged living might have on the relation between resilience and fatigue. It was chosen to only study mediating effects within the limited framework of this study. The hypothesized relationships are illustrated in the model in Figure 1. Attention must be paid to the role of pain, because the hypotheses are mostly based on findings from pain research and because pain and fatigue are strongly related (Schneeberger et al., 2015).

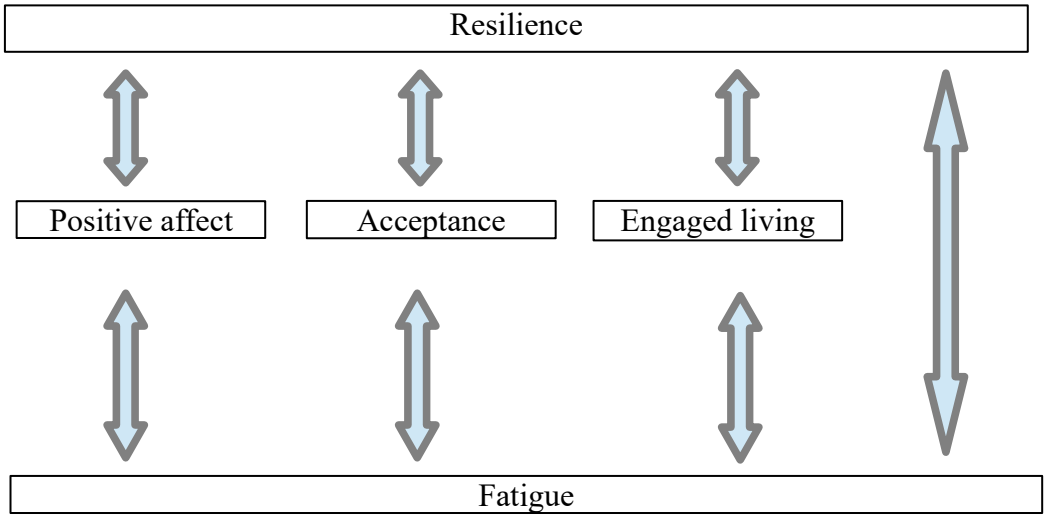

Figure 1

Proposed model of the relationship between resilience and fatigue.

2. Method

2.1 Sample

For the present study, a participant sample from a study from 2015 was used. 154 members of the patient forum 'Reuma research partners' from the 'Reumacentrum Twente' who agreed to participate in surveys were approached. From these patients, 134 were invited to participate in this study via e-mail. 18 e-mail addresses were not active. These 18 patients and the 20 patients who did not report an e-mail address received a postal invitation. Among these, 3 letters could not be delivered. In total, 151 members of the forum were invited for participation, 69 of whom filled in the survey (response percentage: 46%). Because of an assessment error in the postal sample regarding items 9a - i of the SF-36, only the data from the online sample could be taken into analyses (N=57).

Demographic information about the sample can be found in Table 1. The sample consists of considerably more women than men. This is in line with the statement that the prevalence of rheumatic diseases is higher among females (Falsarella et al., 2012). Also the age of sample is representative of the population of patients suffering from rheumatic diseases (Falsarella et al., 2012). RA is clearly the most prevalent rheumatic disease in this sample. According to Anderson et al. (1985), RA is the most common form of rheumatism in general.

Table 1

Sample characteristics

	n	%
Gender		
Female	40	70.2
Male	17	29.8
Rheumatic disease *		
RA	40	70.2
OA	12	21.1
FM	5	8.8
Others	27	47.5
Civil status		
not married/not living together	5	8.8
not married/living together	8	14.0
married	37	64.9
divorced	7	12.3
Level of education		
Low	7	12.3
Medium	27	47.4
High	23	40.3
Work situation		
Paid work, more than 20h/week	12	21.1
Paid work, 20h or less/week	4	7.0
School or study	1	1.8
Incapacitated	11	19.3
Retired	19	33.3
Unemployed	10	17.6

	Minimum	Maximum	Mean	SD
Age	31	88	59.54	11.93
Duration of disease	3	57	17.16	12.10

Note. *multiple answers possible.

2.2 Procedure

As the study was conducted in the Netherlands, the communication with the participants and the survey were in Dutch. In the invitation, the members of the forum were asked if they wanted to participate in a survey about resilience and acceptance among patients suffering from rheumatic diseases. The survey could be completed online or in hard copy. The participants who wanted to complete the survey online received a link to the website where the survey could be answered. Before being able to fill in the survey, they received explicit

information about the study, which served as informed consent. Participants who wanted to fill in the survey on paper received the same information via mail. The letter included general information about the study, an informed consent form and a hard copy of the survey. The signed informed consent form and the completed survey could be sent back to the University of Twente in an enclosed envelope. The study was approved by the Ethics Committee of the faculty of Behavioral Sciences of the University of Twente.

2.3 Measures

The online survey used in this study consists of multiple questionnaires and demographic questions. In the context of the present study, measures of fatigue, resilience, acceptance, positive affect, engaged living and pain were taken into analysis.

Fatigue

Fatigue was assessed with the Vitality scale [VT] from the Short Form 36 Health Survey [SF-36]. The VT consists of 4 items which are rated on a 5-point frequency Likert-scale (from 1='Always' to 5='Never'). The possible scores range from 0 to 100, with a higher score indicating less fatigue. Example items of the VT scale are 'Had u veel energie?' (translation: 'Did you have a lot of energy?') and 'Voelde u zich moe?' (translation: 'Did you feel tired?'). The psychometric qualities of the instrument and the VT scale are good (Ten Klooster et al., 2013). In the present study, a Cronbach's α of .81 was found for the VT scale.

Resilience

Resilience was assessed by two different measures, the Brief Resilience Scale [BRS] and the Resilience Scale – Netherlands Version [RSnl], because of the non-uniform operationalizations of resilience.

The BRS is used as measure for the ability to bounce back or recover from stress (Smith et al. 2008). The BRS consists of one scale with 6 items. The items are rated on a 5-point Likert-scale from 1='I strongly disagree' to 5='I strongly agree'. Items 2, 4 and 6 must be reversed. The score ranges from 6 to 30, with a higher score indicating a stronger ability to bounce back or recover from stress. Example items are 'Ik heb de neiging om snel terug te

veren na moeilijke tijden.' (translation: '.I tend to bounce back quickly after hard times.') and 'Ik heb meestal weinig moeite om door moeilijke tijden heen te komen.' (translation: 'I usually come through difficult times with little trouble.'). The reliability and validity of the instrument are good (Smith et al., 2008). In the present study, a Cronbach's α of .75 was found.

The RSnl is a Dutch adaption of the Wagnild and Young Resilience Scale that assesses protective factors facilitating resilience according to the definition of resilience as personality trait (Leontjevas et al., 2014). It consists of 25 items that are divided into the two subscales 'Personal Competence' and 'Acceptance of Self and Life'. The items are rated on a 4-point Likert-scale ranging from 1='Strongly disagree' to 4='Strongly agree'. Item 11 must be coded reversely. The total score ranges from 25 to 100, with a higher score indicating being more resilient. Examples items are 'Ik kan omgaan met onverwachte problemen.' (translation: 'I can deal with unexpected problem.') and 'Ik ben tevreden met mijzelf.' (translation: 'I am pleased with myself.'). The psychometric qualities of the instrument are good (Portzky et al., 2010). In the present study, a Cronbach's α of .91 was found for the total scale.

Acceptance

Acceptance was assessed by the Acceptance and Action Questionnaire II [AAQ-II]. The AAQ-II consists of 10 items that are rated on a 7-point Likert-scale ranging from 1='Never true' to 7='Always true'. Items 2, 3, 4, 5, 7, 8 and 9 must be coded reversely. The total score lies between 10 and 70, with a higher score indicating a greater amount of acceptance. Example items are 'Zorgen staan mijn succes in de weg' (translation: 'Worries stand in the way of my success' and 'Ik heb controle over mijn leven' (translation: 'I have control over my life'). The psychometric qualities are good (Jacobs et al., 2008). In the present study, a Cronbach's α of .82 was found.

Positive affect

Positive affect was assessed with the subscale 'Positive affect' of the Positive and Negative Affect Schedule [PANAS]. This subscale consists of 10 items describing positive emotional states. The items are rated on a 5-point frequency Likert-scale ranging from 1='Very slightly or not at all' to 5='Extremely'. The score lies between 10 and 50, with a higher score

indicating a higher level of positive affect. Example items are 'Geïnteresseerd' (translation: 'Interested'), 'Sterk' (translation: 'Strong') and 'Actief' (translation: 'Active'). The scale is reliable and valid (Strand et al., 2006). In the present study, a Cronbach's α of .93 was found for this subscale.

Engaged living

Engaged living is measured by the Engaged Living Scale [ELS]. It consists of two subscales, the Valued Living Scale and the Life Fulfillment Scale. The Valued Living Scale assesses the recognition of personal values and the execution of goal-directed actions according to these values and the Life Fulfillment Scale assesses the evaluation and satisfaction of knowing and living according to own values. The scale consists of 16 items that are rated on a 5-point Likert-scale ranging from 1='Strongly disagree' to 5='Strongly agree'. The score range of the subscale goes from 16 to 80, with a higher score indicating living a more engaged life (Trompetter et al., 2013). Example items are 'Ik vind dat mijn gedrag past bij mijn persoonlijke behoeften en verlangens.' (translation: 'I think my behavior is in line with my personal needs and desires.') and 'Ik ben tevreden over hoe ik mijn leven leid.' (translation: 'I am satisfied with the way I live my life.'). The psychometric qualities of the scale are good (Trompetter et al., 2013). In the present study, a Cronbach's α of .93 was found for the total scale.

Pain

The amount of pain experienced during the last week is assessed by a Visual Analog Scale [VAS] going from 0='no pain' to 100='unbearable pain'. The scale consists of a 100 mm long line. The left end of the line marks the score 0, the right end of the line marks the score 100. The respondent reports the amount of pain experienced during the last week by marking a point on the line. The pain score equals the distance between the left end of the line and the mark of the respondent in mm. The higher the score, the higher the amount of pain experienced.

2.4 Analysis

All analyses were conducted with IBM SPSS Statistics 24. Mean substitution per respondent was applied in case of missing values if minimal half of the items of the scale were answered. Descriptive statistics were used to describe the sample and the variables fatigue, pain, resilience, acceptance, positive affect and engaged living. Normality was checked with a Shapiro-Wilk test. Because not all scales are normally distributed, correlations between the variables of the proposed model and between these variables and pain were determined with Spearman's ρ. According to Cohen (1977) correlations are low when ρ lies between .10 and .29, moderate when ρ lies between .30 and .49 and high when ρ is higher than .50.
Multiple linear regression analyses were performed to further examine these relations and to investigate if and to what extent resilience and acceptance, positive affect and engaged living predict variance in fatigue. Concerning the competing explanation that pain predicts the variance in fatigue, pain is added as covariate in the former regression analyses to see if resilience and the resilience factors acceptance, positive affect and engaged living still explained any variance in the level of fatigue. Because of the non-normal distribution of some variables, bootstrapped confidence intervals [CI] are used as indication of significance in addition to *p*-values. If a BCI does not contain 0, the relation is significant.

In order to test the proposed mediation model that the relation between resilience and fatigue is mediated by the resilience-related factors acceptance, positive affect and engaged living, mediation analyses were conducted with the SPSS macro PROCESS (Hayes, 2013). To investigate the mediation in the presence of pain, mediation analyses were conducted again with pain as covariate.

Because neither bootstrapped nor PROCESS regression analyses give a measure of multicollinearity or the standardized regression-coefficient β, standard multiple linear regression analyses were conducted to obtain these measures. VIF-indexes are used as measure of multicollinearity. VIF-indexes below 10 indicate a low probability of multicollinearity, VIF-indexes between 10 and 100 indicate a moderate probability and VIF-indexes above 100 indicate multicollinearity.

The level of significance for statistical tests was 5% or $p \leq 0.05$.

3. Results

In Table 2, means, standard deviations and the minimum and maximum scores of the study variables are shown.

Table 2

Descriptive statistics

	N	Minimum	Maximum	Mean	SD
Fatigue (SF-36 Vitality)	57	23.99	64.58	46.89	9.77
Resilience (BRS)	57	12.00	29.00	20.51	4.20
Resilience (RSnl)	57	62.00	100.00	84.22	9.28
Acceptance (AAQ-II)	57	28.33	68.00	53.29	10.16
Positive affect (PANAS)	57	15.00	47.00	34.96	7.39
Engaged Living (ELS)	57	37.00	79.00	58.56	10.31
Pain (VAS)	55	0.00	88.00	38.58	27.06

The score of fatigue is a norm-based score derived from the American population (M=50, SD=10) (Ware et al., 2000). The fatigue mean score of the present sample is lower, but considering the standard deviation, fatigue levels do not differ substantially between the present sample and the general population .Further, the pain score has a wide range. The respondents experienced different levels of pain intensity. Compared to recently diagnosed RA patients, who had a mean pain score between 28 and 33 (Bode & Taal, 2015), mean pain scores were slightly higher in this sample. The pain mean score is nearly clinically relevant (cut-off ≥ 40) (Bode & Taal, 2015). The mean scores of acceptance, positive affect and engaged living are comparable to the general population (Leontjevas et al., 2014; Crawford & Henry, 2004; Trompetter et al., 2014). Norm-based or cut-off scores do not exist for the BRS and the RSnl for rheumatic patients or the general population. Regarding the standard deviations of BRS and RSnl, one can say that there is variation in resilience among the sample, but not to a great extent. The variables resilience (RSnl) *(W*=0.95, p=.02), acceptance *(W*=0.94, p=.01), positive affect *(W*=0.95, p=.001) and pain *(W*=0.95, p=.005) were not

normally distributed.

The relations between resilience, acceptance, positive affect, engaged living, fatigue and pain

In Table 3, the Spearman's correlations between the study variables can be found.

Table 3

Spearman's correlations (N=57)

	Pain (VAS)[1]	Fatigue (SF-36 Vitality)	Resilience (BRS)	Resilience (RSnl)	Acceptance (AAQ-II)	Positive affect (PANAS)
Fatigue (SF-36 Vitality)	-.63***					
Resilience (BRS)	-.36**	.49***				
Resilience (RSnl)	-.36**	.57***	.47***			
Acceptance (AAQ-II)	-.58***	.59***	.53***	.58***		
Positive affect (PANAS)	-.42**	.61***	.36**	.74***	.59***	
Engaged Living (ELS)	-.46***	.60***	.39**	.68***	.61***	.67***

Note. *p≤.05, **p≤.01, ***p≤.001; [1]N=55.

All variables are significantly related. Pain is negatively correlated with all variables. This means that when pain is higher, the amount of vitality, resilience (BRS and RSnl), acceptance, positive affect and engaged living decreases. All other correlations are positive. When experiencing higher levels of fatigue, participants experience less resilience, acceptance, positive affect and engaged living. Resilience (BRS) and resilience (RSnl) are moderately positively related. Being more resilient is related to higher levels of acceptance, positive affect and engaged living, with the latter two correlating higher with resilience (RSnl) than with resilience (BRS). Striking is the very high correlation between resilience (RSnl) and positive affect. Acceptance, positive affect and engaged living are highly correlated with each other.

The results of the multiple regression analyses can be found in Tables 4 to 7. The VIF-indexes are all below 2.88 indicating that there is no multicollinearity. This means that the combined effect of the variables as well as the distribution of this effect is not biased as a result of mutual correlations between the variables.

Table 4

Multivariate model of fatigue based on resilience (BRS)

Model		B	SE B	LLCI	ULCI	β[1]	VIF[1]	R^2	R^2 change
1	Resilience (BRS)	1.26***	0.24	0.75	1.68	.53***	1.00	.30***	
2	Resilience (BRS)	0.68*	0.26	0.08	1.13	.29*	1.39		
	Acceptance (AAQ-II)	0.11	0.15	-0.20	0.39	.11	2.21		
	Positive affect (PANAS)	0.51**	0.18	0.12	0.84	.39**	2.06		
	Engaged living (ELS)	0.12	0.14	-0.14	0.39	.12	2.34		
								.54***	.25***

Note. *p≤.05, **p≤.01, ***p≤.001. Based on 1000 bootstrap samples. [1]Not based on bootstrapping.

As shown in Table 4, resilience (BRS) explains 30% of the variance in fatigue and is a significant predictor of fatigue. When acceptance, positive affect and engaged living are added, an additional 25% of the variance in fatigue can be explained. The relation of resilience (BRS) with fatigue gets smaller when acceptance, positive affect and engaged living are taken into account. Resilience (BRS) and positive affect have the only significant relations with fatigue in Model 2, with positive affect being stronger related to fatigue than resilience (BRS).

Table 5 shows the results of the multiple regression analysis of resilience (BRS), acceptance, positive affect and engaged living on fatigue when pain is taken into account. Pain explains 39% of the variance in fatigue and has a significant relation with fatigue. Both pain and resilience (BRS) explain 51% of the variance in fatigue and are significantly related to it. The relation of pain with fatigue gets smaller when resilience (BRS) is added. When acceptance, positive affect and engaged living are added to the model (Model 3), an additional 10% of the variance in fatigue can be explained. Pain, resilience (BRS) and positive affect have significant relations with fatigue. Positive affect has a stronger relation with fatigue in the presence of pain than resilience (BRS). Noticeable is that acceptance is almost not related to fatigue in the presence of pain.

Table 5

Multivariate model of fatigue based on resilience (BRS) and pain (VAS)

Model		B	SE B	LLCI	ULCI	β[1]	VIF[1]	R^2	R^2 change
1	Pain (VAS)	-0.23***	0.04	-0.30	-0.16	-.63***	1.00	.39***	
2	Pain (VAS)	-0.18***	0.04	-0.26	-0.11	-.49***	1.15		
	Resilience (BRS)	0.87**	0.24	0.33	1.29	.37***	1.15		
								.51***	.12***
3	Pain (VAS)	-0.13**	0.04	-0.20	-0.04	-.35**	1.61		
	Resilience (BRS)	0.64*	0.25	0.10	1.08	.27**	1.38		
	Acceptance (AAQ-II)	-0.04	0.16	-0.33	0.28	-.05	2.51		
	Positive affect (PANAS)	0.42*	0.18	0.02	0.74	.32**	2.11		
	Engaged living (ELS)	0.11	0.13	-0.13	0.38	.11	2.37		
								.61***	.10**

Note. *p≤.05, **p≤.01, ***p≤.001. Based on 1000 bootstrap samples. [1]Not based on bootstrapping.

Table 6

Multivariate model of fatigue based on resilience (RSnl)

Model		B	SE B	LLCI	ULCI	β[1]	VIF[1]	R^2	R^2 change
1	Resilience (RSnl)	0.64***	0.10	0.44	0.83	.61***	1.00	.37***	
2	Resilience (RSnl)	0.18	0.19	-0.20	0.53	.17	2.88		
	Acceptance (AAQ-II)	0.21	0.14	-0.08	0.47	.22	1.97		
	Positive affect (PANAS)	0.46*	0.20	0.00	0.83	.35*	2.49		
	Engaged living (ELS)	0.06	0.18	-0.24	0.47	.07	2.81		
								.49***	.13**

Note. *p≤.05, **p≤.01, ***p≤.001. Based on 1000 bootstrap samples. [1]Not based on bootstrapping.

Regarding resilience according to the RSnl, resilience (RSnl) explains 37% of the variance in fatigue and is a significantly related to fatigue (Table 6). It explains more of the variance in and has a stronger relation with fatigue than resilience (BRS). Table 6 shows that when acceptance, positive affect and engaged living are added, an additional 13% of the variance in fatigue can be explained. In Model 2 positive affect has the only significant relation with fatigue when considering the *p*-values. But the CIs entails 0, which means that positive affect is not significantly related to fatigue in the model. This could be due to a rounding issue. The lower limit of the CI of acceptance is close to 0, which might indicate that also acceptance is related to fatigue.

Table 7

Multivariate model of fatigue based on resilience (RSnl) and pain (VAS)

Model		B	SE B	LLCI	ULCI	β[1]	VIF[1]	R^2	R^2 change
1	Pain (VAS)	-0.23***	0.04	-0.30	-0.15	-.63***	1.00	.39***	
2	Pain (VAS)	-0.17***	0.04	-0.24	-0.09	-.47***	1.19		
	Resilience (RSnl)	0.43***	0.10	0.22	0.63	.40***	1.19		
								.53***	.14***
3	Pain (VAS)	-0.14**	0.04	-0.22	-0.05	-.38**	1.60		
	Resilience (RSnl)	0.18	0.17	-0.17	0.50	.17	2.88		
	Acceptance (AAQ-II)	0.03	0.15	-0.27	0.31	.03	2.37		
	Positive affect (PANAS)	0.35	0.21	-0.13	0.74	.27	2.59		
	Engaged living (ELS)	0.07	0.15	-0.20	0.39	.07	2.85		
								.57**	.04

Note. *p≤.05, **p≤.01, ***p≤.001. Based on 1000 bootstrap samples. [1]Not based on bootstrapping.

In Table 7, the results of the multiple regression analysis of fatigue on resilience (RSnl), acceptance, positive affect and engaged living when pain is taken into account can be found. Pain and resilience (RSnl) explain 53% of the variation in fatigue and are both significantly

related to fatigue. When acceptance, positive affect and engaged living are added to the model, 57% of the variance in fatigue can be explained, but the additional variance is not significant. In this model (Model 3) only pain has a significant relation with fatigue. As in Model 3 of resilience (BRS) and pain, the acceptance is almost not related to fatigue.

Despite the high Spearman's correlations of acceptance and engaged living with fatigue and resilience (RSnl), no significant relations with fatigue were found for acceptance and engaged living when resilience or resilience and pain were taken into account. Acceptance was almost not related with fatigue in presence of both resilience (BRS) and pain and resilience (RSnl) and pain (Tables 7 and 5). When it was not accounted for pain, the relations of acceptance with fatigue were stronger but still not significant. However, the lower limits of the CIs of acceptance were close to 0 (Tables 4 and 6).

Acceptance, positive affect and engaged living as mediators

Mediating effects of acceptance, positive affect and engaged living in the relation between resilience and fatigue were studied. The mediating effects are shown in Table 8 for resilience (BRS) and in Table 9 for resilience (RSnl).

Table 8

Mediation of acceptance, positive affect and engaged living on the relation between resilience (BRS) and fatigue

Independent variable	Mediator	Unstandardized				Standardized			
		B	SE B	LLCI	ULCI	β	SE β	LLCI	ULCI
Resilience (BRS)	Acceptance (AAQ-II)	0.13	0.18	-0.24	0.51	.06	0.08	-0.10	0.21
	Positive affect (PANAS)	0.34	0.17	0.09	0.77	.15	0.07	0.04	0.32
	Engaged living (ELS)	0.11	0.14	-0.13	0.42	.05	0.06	-0.06	0.17
Resilience (BRS) with Pain (VAS) as covariate	Acceptance (AAQ-II)	-0.04	0.14	-0.39	0.20	-.02	0.07	-0.19	0.10
	Positive affect (PANAS)	0.19	0.14	0.00	0.59	.09	0.07	0.00	0.28
	Engaged living (ELS)	0.08	0.11	-0.09	0.35	.04	0.05	-0.05	0.17

Note. Based on 5000 bootstrap samples.

A mediating effect was found for positive affect in the relation between resilience (BRS) and fatigue when pain was not taken into account. Resilience (BRS) is indirectly related to fatigue through positive affect. Because resilience (BRS) still has a significant direct relation with fatigue in the presence of positive affect (Table 4), positive affect is a partial mediator of the relation. The mediating effect vanishes when pain is taken into account. It is noticeable that the lower limit of the CI of positive affect in the presence of pain is 0, but a rounding issue might be possible. No other mediating effects were found in the relation between resilience (BRS) and fatigue.

Comparable results were obtained for the relation between resilience (RSnl) and fatigue. A mediating effect was found for positive affect in the relation between resilience (RSnl) and fatigue when pain is not taken into account. Resilience is indirectly related to fatigue through positive affect. Resilience (RSnl) does not have a direct relation with fatigue in the presence of positive affect (Table 6), thus, positive affect does fully mediate the relation between resilience (RSnl) and fatigue. When pain is taken into account, the mediating effect of positive affect vanishes. No other mediating effects were found in the relation between resilience (RSnl) and fatigue, although the CI of acceptance is close to significance.

Table 9

Mediation of acceptance, positive affect and engaged living on the relation between resilience (RSnl) and fatigue

Independent variable	Mediator	Unstandardized				Standardized			
		B	SE B	LLCI	ULCI	β	SE β	LLCI	ULCI
Resilience (RSnl)	Acceptance (AAQ-II)	0.14	0.09	-0.04	0.33	.14	0.09	-0.04	0.31
	Positive affect (PANAS)	0.27	0.12	0.02	0.51	.25	0.11	0.02	0.46
	Engaged living (ELS)	0.05	0.14	-0.23	0.34	.05	0.14	-0.22	0.33
Resilience (RSnl) with Pain (VAS) as covariate	Acceptance (AAQ-II)	0.01	0.08	-0.15	0.16	.02	0.09	-0.16	0.18
	Positive affect (PANAS)	0.18	0.12	-0.04	0.42	.20	0.12	-0.05	0.43
	Engaged living (ELS)	0.52	0.12	-0.19	0.27	.06	0.13	-0.20	0.30

Note. Based on 5000 bootstrap samples.

4. Discussion

The goal of the present study was to gain a better understanding of the relation between resilience and fatigue in patients with rheumatic diseases. It was proposed that the relation between resilience and fatigue was mediated by acceptance, positive affect and engaged living. These factors have previously shown beneficial effects on pain among patients with different kinds of rheumatic diseases. This is the first study that examines the relations of these factors with resilience and fatigue in rheumatic patients.

In the present study, resilience was assessed with two different types of measures, the Brief Resilience Scale (BRS), indicating the ability to bounce back from stress, and the Resilience Scale (RSnl), assessing resilience as personality trait. The two kinds of resilience were found to be only moderately related, but showed comparable results. Resilience is stronger correlated with fatigue than with pain. Acceptance, positive affect and engaged living are associated with less pain, less fatigue and more resilience. Correlations are stronger with fatigue than with pain and with resilience as personality trait than with resilience as ability. In the tested multivariate model, resilience and positive affect are directly related to fatigue. When pain is taken into account, the direct relation of positive affect remains in the presence of resilience as the ability to bounce back, but vanishes in the presence of resilience as personality trait. Positive affect partly mediates the relation between resilience as ability to bounce back and fatigue, and fully mediates the relation between resilience as personality trait and fatigue. The mediating effects vanish in the presence of pain. These findings will be discussed in the following.

Positive affect, resilience and fatigue

Positive affect was associated with higher levels of resilience and lower levels of fatigue. This is in accordance with Slepian et al. (2016) who states that high-resilient individuals report more positive emotions than individuals low in resilience, and Pettit et al. (2001) who found higher levels of fatigue in RA patients with low positive affect. Positive affect mediated the relation between resilience and fatigue. Resilience as ability to bounce back was partly

indirectly related to fatigue through positive affect. The relation between resilience as personality trait and fatigue was fully mediated by positive affect. Positive affect seems to play an important role in resilience and health outcomes as fatigue (Dockray & Steptoe, 2010). The beneficial and restorative effects of positive affect are well documented, for example in the broaden-and-build theory of (Frederickson, 2001). Targeting positive affect might be a promising approach in the treatment of fatigue.

Acceptance, resilience and fatigue

In the present study, acceptance was associated with higher levels of resilience and lower levels of fatigue, supporting evidence from other studies (Repping-Wuts et al., 2008; Ramirez-Maestre & Esteve, 2014). But when the role of resilience in relation to fatigue was taken into account, the relation of acceptance with fatigue vanished. A possible explanation for this might be that resilience implies acceptance. Supporting evidence for this explanation is given by Ramirez-Maestre & Esteve (2014) who stated that resilience and acceptance are interconnected and that resilience contains measures of acceptance. However, the relation of acceptance and fatigue in the presence of resilience as personality trait, was close to significant as well as the indirect relation of resilience as personality trait on fatigue through acceptance. Also, there was no indication of multicollinearity. A replication of this study with a bigger sample might reveal more distinct results. It might be concluded that acceptance possibly plays a role in the relation between resilience as personality trait and fatigue.

Engaged living, resilience and fatigue

Engaged living could be associated with resilience as well as fatigue, underlining results from previous studies (Froh et al., 2010; Bode & Taal, 2015). In the present study, no indication was found that engaged living plays a role in the relation between resilience and fatigue. Even if resilient individuals are more likely to engage in valued activities (Ruiz-Párraga & López-Martínez, 2015), this does not affect the level of fatigue experienced by these individuals.

Resilience as ability and resilience as personality trait

No universally accepted definition of resilience exists which leads to different

operationalizations of resilience (Leontjevas et al., 2014). Therefore, it was chosen to assess resilience with two different operationalizations: resilience as the ability to bounce back, assessed with the Brief Resilience Scale (BRS), and resilience as personality trait with predispositional characteristics that facilitate overcoming adversity (Resnick & Inguito, 2011), which is assessed with the Dutch version of the Resilience Scale (RSnl). The relation between these two kinds of resilience was only moderately high indicating that the two measurements of resilience do not assess the same resilience concept. Nevertheless, both kinds of resilience showed comparable results regarding their correlation with pain.

Spearman's correlations differed for the two kinds of resilience regarding the other studied variables. Associations with fatigue, acceptance, positive affect and engaged living were stronger with resilience as personality trait than with resilience as ability. Especially the association with positive affect and engaged living differed strikingly between the two concepts of resilience.

In the multivariate model, engaged living was not found to play a role in the relation between resilience and fatigue, but mediating effects were found for positive affect. Positive affect fully mediated the relation between resilience as personality trait and fatigue, but only partially mediated the relation between resilience as ability and fatigue. A possible explanation for the difference in mediation is the conceptual difference between resilience as personality trait and resilience as ability. Resilience as personality trait entails predispositional characteristics through which one can adapt to adversity (Slepian et al., 2016). Positive affect might be considered part of the predispositional characteristics of resilient individuals as the influence of resilience as personality trait on fatigue depends completely on positive affect. Resilience as ability does not explain resources that could facilitate positive outcomes but focuses on the ability of the patient to bounce back, recover from stress or to resist negative influences of significant events (Leontjevas et al., 2014). The partial mediation of positive affect on the relation between resilience as ability and fatigue means that the influence of resilience as ability cannot fully be explained by the role of positive affect and that resilience as ability has a direct influence on fatigue. An explanation for this may be that individuals who are able to bounce back from stress have more opportunities to experience positive emotions and that both positive affect and resilience have direct beneficial effects on fatigue

(Smith et al., 2008; Pettit et al., 2001).

More research is needed to understand the concept of resilience, how it can be best operationalized and what the underlying mechanisms are. Studying resilience is problematic, because comparing different studies of resilience might be difficult to impossible due to its diverse definitions and operationalizations (Johnston et al., 2015). There is a clear need to establish an unambiguous definition of resilience. Nevertheless, resilience is an important predictor of the adaption to health challenges in general (Slepian et al., 2016). The results of the present study underline that both forms of resilience are important.

Pain

This study is mostly based on findings from pain research. Because pain and fatigue are strongly related (Schneeberger et al., 2015), it was assumed that the findings might also apply to fatigue. The present study confirmed a strong relation between pain and fatigue. Moreover, resilience, acceptance, positive affect and engaged living were stronger associated with fatigue than with pain. This supports the assumption that the found beneficial effects of resilience, positive affect, acceptance and engaged living on pain might also apply to fatigue and may be even more important in fatigue than in pain (Friborg et al., 2006; Slepian et al., 2016; Trompetter et al., 2015; Trompetter et al., 2013). But attention must be paid to the role of pain in these relations. In fact, the relation between resilience and fatigue got weaker when pain was taken into account.

Further, when pain is taken into account, positive affect does no longer mediate the relation between resilience as personality trait and fatigue and is no longer related to fatigue. The relation of positive affect with fatigue appears to depend on pain when regarding resilience as personality trait. It is possible that pain limits opportunities to experience positive affect (Zautra et al., 1995). However, the relation between positive affect and fatigue remains in the presence of pain when resilience is assessed as ability. This might be due to the direct relation that resilience as ability has with fatigue which possibly allows for more experiences of positive affect despite pain.

Also the relation of acceptance with fatigue in the presence of both kinds of resilience vanished completely when pain was taken into account. Although the relation of acceptance

with fatigue in the presence of resilience was not significant, even when pain was not accounted for, the lack of any relation was striking. A possible explanation might be that experiencing pain decreases not only pain acceptance (Trompetter et al., 2015) but acceptance of the illness or its symptoms in general.

This means that pain does play a role in the relation between fatigue and resilience. The results found in this study highlight the need to further examine the relationship between pain, resilience and fatigue with bigger study samples to obtain more distinct results.

The present study gives new insights into the relation between fatigue and resilience and the role of acceptance, positive affect and engaged living in this relation. Also the role of pain has been considered in this study, which is important as both resilience and fatigue have been strongly linked to pain (Friborg et al., 2006; Schneeberger et al., 2015). The results provide a good basis for future research and clinical trials to further investigate the relation between resilience and fatigue and the cause-and-effect relations. Another important feature of this study is that all used instruments have good psychometric qualities and reliability was proven to be excellent, which contributes to the accuracy of the study results. Furthermore, the sample used in this study is representative of the population of rheumatic patients regarding gender, age and the kind of rheumatic disease.

Regarding the mean levels of fatigue, acceptance, positive affect and engaged living, the study sample was comparable to the general population. This might cause the results to be less conclusive for the clinical population of rheumatic patients. Nevertheless, there were respondents with clinical levels of fatigue. A replication of the study with respondents with higher levels of fatigue will erase doubts. Also a sample with a greater variance in resilience might be favorable. Moreover, the sample size was small. Due to this, the power of the used statistical tests might be too low. Replication of the study with a larger sample will create clearer results. The role of acceptance might gain significance. The instruments assessing resilience were reliable, but the addition of an instrument assessing the amount of experienced adversity based on fatigue might be useful as experiencing adversity is a condition of resilience (Friborg et al., 2006). Further, not only mediation of acceptance, positive affect and engaged living in the relation between resilience and fatigue should be studied, but also

moderation to gain a more complete picture of the relation between resilience and fatigue. Moreover, the different relations should not only take pain into account, as done in this study, but also other factors that might have an influence. For example, resilience and acceptance were found to increase with age (Portzkyet al., 2010; Péntek et al., 2014) and females tend to have higher levels of fatigue (Nikolaus et al., 2013). Furthermore, the duration of the disease and the level of disability have been associated with fatigue (Novaes et al., 2011). Also the kind of the rheumatic disease should be considered. RA-related fatigue was more strongly linked to pain, whereas OA-related fatigue was more related to disability (Novaes et al., 2011). FM patients showed lower levels of positive affect (Zautra, 2005). Another important factor to account for is the presence of affective disorders as depression. Depression is prevalent among patients with rheumatic diseases as RA (Bode & Taal, 2015). Evers et al. (2011) state that 20 – 40% of rheumatic patients fit criteria for a depression or anxiety diagnosis. Further, depression has been linked to fatigue and low levels of positive affect and is a risk factor to resilience (Davydov et al., 2010). Last but not least, the present study is based on cross-sectional data. Causal conclusions are inappropriate. The relations should further be investigated in longitudinal studies that assess changes in resilience, fatigue and positive affect as well as acceptance, and reveal causal effects on fatigue in rheumatic patients.

In spite of these limitations, the present study offers important new insights in the relation between resilience and the related factors acceptance, positive affect and engaged living with fatigue and correlational evidence that these relations are worth of further pursuit. The impact of fatigue on rheumatic patients is high, but fatigue is often denied in the treatment of rheumatic diseases (Bode & Taal, 2015). By identifying factors that might decrease fatigue in rheumatic patients, new treatments for fatigue can be developed. Resilience, positive affect and possibly also acceptance are promising targets to be approached in the treatment of fatigue in rheumatic patients, but first the causality of this relation must be studied. The beneficial effects of resilience, positive affect and acceptance on fatigue might also apply for other population suffering from fatigue.

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6. Appendix

6.1 Letter of Invitation

ONDERWERP
Vragenlijst Veerkracht, acceptatie en welzijn bij reumapatiënten

Geachte heer of mevrouw,

U bent lid van het reumapatiëntenforum van het Reumacentrum Twente. U heeft aangegeven benaderd te kunnen worden voor het deelnemen aan vragenlijstonderzoek. Wij willen u vragen of u wilt deelnemen aan een onderzoek naar het welbevinden en veerkracht van mensen met een reumatische aandoening. Veerkracht is het vermogen om te herstellen na het meemaken van een stressvolle situatie. In dit onderzoek willen we onderzoeken in hoeverre veerkracht gerelateerd is aan het welbevinden van mensen met reuma. Het onderzoek wordt uitgevoerd door de vakgroep Psychologie, Gezondheid en Technologie van de Universiteit Twente in samenwerking met het Reumacentrum Twente.

Wij, Maaike Leenman en Sarah Kurney, zijn studenten psychologie aan de Universiteit Twente en voeren dit onderzoek uit als onderdeel van onze studie. Het onderzoek wordt uitgevoerd onder begeleiding van Dr. E. Taal en Prof. Dr. K.M.G. Schreurs van de Universiteit Twente.

Bijgesloten bij deze brief vindt u de vragenlijst en het geïnformeerde toestemmingsformulier. Als u mee wilt doen aan deze studie vragen wij u om de vragenlijst in te vullen en het toestemmingsformulier te ondertekenen. U kunt de vragenlijst en het ondertekende toestemmingsformulier terug sturen naar de Universiteit Twente in de bijgeleverde retour-envelop. U hoeft hier geen postzegel op te plakken.

Als u nog vragen heeft of als er onduidelijkheden zijn, zijn wij telefonisch of per e-mail te bereiken. Hieronder vindt u onze contactgegevens.
hier uw tekst

Met vriendelijke groet,

Sarah Kurney,
e-mail: s.kurney@student.utwente.nl

Maaike Leenman
e-mail: m.p.leenman@student.utwente.nl
Tel: 06-81408151

6.2 Informed Consent Form

Welkom bij het vragenlijstonderzoek over veerkracht, welbevinden en acceptatie bij mensen met reumatische aandoeningen. Voordat u begint met het invullen van de vragenlijst, willen we u graag meer uitleg geven.

Het doel van dit onderzoek is meer inzicht verkrijgen in de samenhang tussen mentaal welbevinden, acceptatie en veerkracht bij reumapatiënten. Veerkracht is het vermogen om te herstellen na stress of tegenslag, waardoor mensen zich mentaal sterker voelen en meer grip op het leven ervaren. Veerkracht is van groot belang voor reumapatiënten, want zelfs als patiënten de ziekte onder controle hebben, worstelen zij vaak nog met pijn, vermoeidheid, angstige of sombere gevoelens, en lichamelijke en sociale beperkingen. Dit vragenlijstonderzoek kan een belangrijke bijdrage leveren aan het ontwikkelen van interventieprogramma's om reumapatiënten te ondersteunen bij het omgaan met hun ziekte en hun veerkracht te versterken. Het invullen van de vragenlijst duurt ongeveer 30-45 minuten. De vragenlijst begint met vragen over de achtergrond gegevens over geslacht, leeftijd en dergelijke. Hierna volgen een aantal vragen die te maken hebben met onder andere veerkracht, welbevinden en acceptatie.

U kunt altijd, zonder opgave van redenen, stoppen met het onderzoek als u zich niet op uw gemak voelt of een vraag niet wilt beantwoorden. Uw behandelende arts zal daarover niet geïnformeerd worden. Afzien van deelname heeft geen enkel gevolg voor uw behandeling bij het ziekenhuis.

De gegevens verkregen uit dit onderzoek zullen anoniem verwerkt worden en in rapporten over het onderzoek zullen gepubliceerde gegevens strikt vertrouwelijk en anoniem verwerkt worden en niet te herleiden zijn naar personen.

We willen u graag vragen om toestemming te geven voor deelname aan het vragenlijstonderzoek:

Ik heb bovenstaande tekst gelezen en ik ben me ervan bewust dat deelname aan dit vragenlijstonderzoek geheel vrijwillig is. Hierbij geef ik toestemming om mijn gegevens voor dit onderzoek te gebruiken.

Naam: …….

Geboortedatum:……..

Handtekening deelnemer: …… Datum:……..

Handtekening onderzoeker: …… Datum:……..

6.3 Survey

VRAGENLIJST
VEERKRACHT, ACCEPTATIE EN WELZIJN BIJ REUMAPATIËNTEN

VAKGROEP PSYCHOLOGIE, GEZONDHEID EN TECHNOLOGIE

Oktober 2015

Contactpersoon:
Maaike Leenman
e-mail: m.p.leenman@student.utwente.nl
Tel: 06-81408151

Beantwoord de volgende vragen door een ☐ in het hokje te plaatsen, dat het meest overeenkomt met uw antwoord.

Hier volgen eerst algemene vragen over uzelf:

Wat is uw geslacht? ☐ Man ☐ Vrouw

Wat is uw leeftijd: ____

Welke vorm(en) van reuma heeft u?

☐ reumatoïde artritis
☐ artrose
☐ S.L.E.
☐ fibromyalgie
☐ sclerodermie (systematische sclerose)
☐ artritis psoriatica
☐ syndroom van Reiter
☐ jicht
☐ lage rugpijn
☐ tendinitis / bursitis
☐ osteoporose
☐ ziekte van Bechterew
☐ weet ik niet
☐ anders, nl: _____

Sinds wanneer heeft u last van uw reumatische aandoening? (Wilt u globaal het jaar invullen)

_____

Wat is uw burgerlijke staat?

☐ ongehuwd / niet samenwonend
☐ ongehuwd / samenwonend
☐ gehuwd
☐ weduwe / weduwnaar
☐ gescheiden

Wat is uw hoogst genoten opleiding?

☐ Geen opleiding

☐ Basisonderwijs (lager onderwijs)

☐ Lager beroepsonderwijs (LBO, huishoudschool, LEAO, LTS, etc.)

☐ MAVO, (M)ULO, 3-jarige HBS, VMBO

☐ Middelbaar beroepsonderwijs (bijv. MTS, MEAO)

☐ 5-jarige HBS, HAVO, MMS, atheneum, gymnasium

☐ Hoger beroepsonderwijs (bijv. HTS, HEAO)

☐ Wetenschappelijk onderwijs (universiteit)

Wat is de beste omschrijving van uw huidige arbeidssituatie? (Wilt u één antwoord geven)

☐ betaald werk, meer dan 20 uur per week

☐ betaald werk, 20 uur of minder per week

☐ onbetaald werk/ vrijwilligerswerk

☐ huishouden

☐ school of studie

☐ arbeidsongeschikt (WAO/WIA)

☐ gepensioneerd (AOW, VUT)

☐ werkloos

De volgende vragen beschrijven gevoelens die mensen kunnen hebben. Lees iedere uitspraak zorgvuldig door en vink het antwoord aan dat het best weergeeft hoe vaak u dat gevoel had gedurende de afgelopen maand.

In de afgelopen maand, hoe vaak had u het gevoel...

	Nooit	Eén of twee keer	Ongeveer 1 keer per week	2 of 3 keer per week	Bijna elke dag	Elke dag
...dat u gelukkig was?	☐	☐	☐	☐	☐	☐
... dat u geïnteresseerd was in het leven?	☐	☐	☐	☐	☐	☐
...dat u tevreden was?	☐	☐	☐	☐	☐	☐
...dat u iets belangrijks hebt bijgedragen aan de samenleving?	☐	☐	☐	☐	☐	☐
...dat u deel uitmaakte van een gemeenschap (zoals een sociale groep, uw buurt, uw stad)?	☐	☐	☐	☐	☐	☐
...dat onze samenleving beter wordt voor mensen?	☐	☐	☐	☐	☐	☐
...dat mensen in principe goed zijn?	☐	☐	☐	☐	☐	☐
...dat u begrijpt hoe onze maatschappij werkt?	☐	☐	☐	☐	☐	☐
...dat u de meeste aspecten van uw persoonlijkheid graag mocht?	☐	☐	☐	☐	☐	☐
...dat u goed kon omgaan met uw alledaagse verantwoordelijkheden?	☐	☐	☐	☐	☐	☐

In de afgelopen maand, hoe vaak had u het gevoel...

	Nooit	Eén of twee keer	Ongeveer 1 keer per week	2 of 3 keer per week	Bijna elke dag	Elke dag
...dat u warme en vertrouwde relaties met anderen had?	☐	☐	☐	☐	☐	☐
...dat u werd uitgedaagd om te groeien of een beter mens te worden?	☐	☐	☐	☐	☐	☐
...dat u zelfverzekerd uw eigen ideeën en meningen gedacht en geuit hebt?	☐	☐	☐	☐	☐	☐
...dat uw leven een richting of zin heeft?	☐	☐	☐	☐	☐	☐

Geef aan in welke mate u het eens bent met elk van de onderstaande stellingen:

	Helemaal niet mee eens	Niet mee eens	Neutraal	Mee eens	Helemaal mee eens
Ik heb de neiging om snel terug te veren na moeilijke tijden.	☐	☐	☐	☐	☐
Ik vind het moeilijk om stressvolle gebeurtenissen te doorstaan.	☐	☐	☐	☐	☐
Ik heb niet veel tijd nodig om van een stressvolle gebeurtenis te herstellen.	☐	☐	☐	☐	☐
Het is moeilijk voor mij om verder te gaan als er iets vervelends gebeurt.	☐	☐	☐	☐	☐
Ik heb meestal weinig moeite om door moeilijke tijden heen te komen.	☐	☐	☐	☐	☐
Ik heb de neiging veel tijd te nemen om over tegenslagen in mijn leven heen te komen.	☐	☐	☐	☐	☐

Wat past bij u? Geef aan in welke mate u het eens bent met de volgende stellingen:

	Helemaal oneens	Gedeeltelijke oneens	Gedeeltelijke eens	Helemaal eens
Als ik plannen maak voer ik ze uit.	☐	☐	☐	☐
Ik red het op de een of andere manier wel.	☐	☐	☐	☐
Ik kan meer op mezelf rekenen, dan ik verwacht dat anderen op zichzelf kunnen rekenen.	☐	☐	☐	☐

Wat past bij u? Geef aan in welke mate u het eens bent met de volgende stellingen:

	Helemaal oneens	Gedeeltelijke oneens	Gedeeltelijke eens	Helemaal eens
Geïnteresseerd blijven in dingen is belangrijk voor mij.	☐	☐	☐	☐
Ik kan op mezelf zijn als dat nodig is.	☐	☐	☐	☐
Ik ben trots op de dingen die ik heb bereikt in mijn leven.	☐	☐	☐	☐
Ik kan omgaan met onverwachte problemen.	☐	☐	☐	☐
Ik ben tevreden met mijzelf.	☐	☐	☐	☐
Ik heb het gevoel dat ik veel dingen tegelijkertijd aankan.	☐	☐	☐	☐
Ik ben vastberaden.	☐	☐	☐	☐
Ik twijfel aan de zin van het leven.	☐	☐	☐	☐
Ik pak problemen aan zoals ze zich voordoen.	☐	☐	☐	☐
Ik sla mij door moeilijke momenten heen omdat ik al eerder moeilijke momenten heb meegemaakt.	☐	☐	☐	☐
Ik heb zelfdiscipline.	☐	☐	☐	☐
Ik blijf geïnteresseerd in dingen.	☐	☐	☐	☐
Ik vind zelfs in moeilijke tijden wel iets om over te lachen.	☐	☐	☐	☐

Wat past bij u? Geef aan in welke mate u het eens bent met de volgende stellingen:

	Helemaal oneens	Gedeeltelijke oneens	Gedeeltelijke eens	Helemaal eens
Mijn geloof in mezelf helpt me door moeilijke momenten.	☐	☐	☐	☐
In een noodgeval ben ik iemand waar mensen op kunnen rekenen.	☐	☐	☐	☐
Ik bekijk een situatie op verschillende manieren.	☐	☐	☐	☐
Ik kan mezelf dwingen dingen te doen, zelfs als ik daar geen zin in heb.	☐	☐	☐	☐
Mijn leven heeft zin.	☐	☐	☐	☐
Ik blijf niet stilstaan bij dingen waar ik niets aan kan doen.	☐	☐	☐	☐
In een moeilijke situatie vind ik altijd een uitweg.	☐	☐	☐	☐
Ik heb genoeg energie om te doen wat ik moet doen.	☐	☐	☐	☐

Deze vragenlijst gaat over uw standpunten t.a.v. uw gezondheid. Met behulp van deze gegevens kan worden bijgehouden hoe u zicht voelt en hoe goed u in staat bent uw gebruikelijke bezigheden uit te voeren.

1) Hoe zou u over het algemeen uw gezondheid noemen?

Uitstekend	Zeer goed	Goed	Matig	Slecht
☐	☐	☐	☐	☐

2) Hoe beoordeelt u nu uw gezondheid over het algemeen, vergeleken met een jaar geleden?

Veel beter nu dan een jaar geleden	Wat beter nu dan een jaar geleden	Ongeveer hetzelfde nu als een jaar geleden	Wat slechter nu dan een jaar geleden	Veel slechter nu dan een jaar geleden
☐	☐	☐	☐	☐

3) **De volgende vragen gaan over bezigheden die u misschien doet op een doorsnee dag. Wordt u door uw gezondheid op dit moment beperkt bij deze bezigheden? Zo ja, in welke mate?**

	Ja, ernstig beperkt	Ja, een beetje beperkt	Nee, helemaal niet beperkt
Forse inspanning, zoals hardlopen, tillen van zware voorwerpen, een veeleisende sport beoefenen	☐	☐	☐
Matige inspanning, zoals een tafel verplaatsen, stofzuigen, zwemmen of fietsen	☐	☐	☐
Boodschappen tillen of dragen	☐	☐	☐
Een paar trappen oplopen	☐	☐	☐
Eén trap oplopen	☐	☐	☐
Bukken, knielen of hurken	☐	☐	☐
Meer dan een kilometer lopen	☐	☐	☐
Een paar honderd meter lopen	☐	☐	☐
Ongeveer honderd meter lopen	☐	☐	☐
Uzelf wassen of aankleden	☐	☐	☐

4) Hoe vaak hebt u in de afgelopen 4 weken, een van de volgende problemen bij uw werk of andere dagelijkse bezigheden gehad, ten gevolge van uw lichamelijke gezondheid?

	Altijd	Meestal	Soms	Zelden	Nooit
U besteedde minder tijd aan werk of andere bezigheden	☐	☐	☐	☐	☐
U heeft minder bereikt dan u zou willen	☐	☐	☐	☐	☐
U was beperkt in het soort werk of andere bezigheden	☐	☐	☐	☐	☐
U had moeite om uw werk of andere bezigheden uit te voeren (het kostte u bv. extra inspanning)	☐	☐	☐	☐	☐

5) Hoe vaak hebt u in de afgelopen 4 weken, een van de volgende problemen ondervonden bij uw werk of andere dagelijkse bezigheden ten gevolge van emotionele problemen (zoals depressieve of angstige gevoelens)?

	Altijd	Meestal	Soms	Zelden	Nooit
U besteedde minder tijd aan werk of andere bezigheden	☐	☐	☐	☐	☐
U heeft minder bereikt dan u zou willen	☐	☐	☐	☐	☐
U deed uw werk of andere bezigheden niet zo zorgvuldig als gewoonlijk	☐	☐	☐	☐	☐

6) In hoeverre hebben uw lichamelijke gezondheid of emotionele problemen u gedurende de afgelopen 4 weken gehinderd in uw normale omgang met familie, vrienden of buren, of bij activiteiten in groepsverband?

Helemaal niet	Enigszins	Nogal	Veel	Heel erg veel
☐	☐	☐	☐	☐

7) Hoeveel lichamelijke pijn heeft u de afgelopen 4 weken gehad?

Geen	Heel licht	Licht	Nogal	Ernstig	Heel ernstig
☐	☐	☐	☐	☐	☐

8) In welke mate bent u de afgelopen 4 weken door pijn gehinderd in uw normale werk (zowel werk buitenshuis als huishoudelijk werk)?

Helemaal niet	Een klein beetje	Nogal	Veel	Heel erg veel
☐	☐	☐	☐	☐

9) Deze vragen gaan over hoe u zich voelt en hoe het met u ging in de afgelopen 4 weken. Wilt u a.u.b. bij elke vraag het antwoord geven dat het best benadert hoe u zich voelde. Hoe vaak gedurende de afgelopen 4 weken...

	Helemaal niet mee eens	Niet mee eens	Neutraal	Mee eens	Helemaal mee eens
Voelde u zich levenslustig?	☐	☐	☐	☐	☐
Was u erg zenuwachtig?	☐	☐	☐	☐	☐
Zat u zo in de put dat niets u kon opvrolijken?	☐	☐	☐	☐	☐
Voelde u zich rustig en tevreden?	☐	☐	☐	☐	☐
Had u veel energie?	☐	☐	☐	☐	☐
Voelde u zich somber en neerslachtig?	☐	☐	☐	☐	☐
Voelde u zich uitgeput?	☐	☐	☐	☐	☐
Voelde u zich gelukkig?	☐	☐	☐	☐	☐
Voelde u zich moe?	☐	☐	☐	☐	☐

10) Hoe vaak hebben uw lichamelijke gezondheid of emotionele problemen u gedurende de afgelopen 4 weken gehinderd bij uw sociale activiteiten (zoals vrienden of familie bezoeken, etc.)?

Altijd	Meestal	Soms	Zelden	Nooit
☐	☐	☐	☐	☐

11) Hoe JUIST of ONJUIST is elk van de volgende uitspraken voor u?

	Volkomen juist	Grotendeels juist	Weet ik niet	Grotendeels onjuist	Volkomen onjuist
Ik lijk wat gemakkelijker ziek te worden dan andere mensen	☐	☐	☐	☐	☐
Ik ben even gezond als andere mensen die ik ken	☐	☐	☐	☐	☐
Ik verwacht dat mijn gezondheid achteruit zal gaan	☐	☐	☐	☐	☐
Mijn gezondheid is uitstekend	☐	☐	☐	☐	☐

Hoeveel pijn had u als gevolg van uw reuma in de afgelopen week? Geef dit aan door een verticaal streepje te zetten op de gewenste plek op de zwarte lijn. Helemaal links is 'helemaal geen pijn' en helemaal rechts is 'ondraaglijke pijn'.

Helemaal geen pijn — Ondraaglijke pijn

De volgende woorden geven verschillende gevoelens en emoties aan. Vink alstublieft het vakje aan wat weergeeft in hoeverre u zich zo gevoeld heeft in de afgelopen week.

	Nauwelijks of helemaal niet	Een beetje	Matig	Best veel	In sterke mate
Geïnteresseerd	☐	☐	☐	☐	☐
Uitgelaten	☐	☐	☐	☐	☐
Sterk	☐	☐	☐	☐	☐
Enthousiast	☐	☐	☐	☐	☐
Trots	☐	☐	☐	☐	☐
Alert	☐	☐	☐	☐	☐
Geïnspireerd	☐	☐	☐	☐	☐
Vastberaden	☐	☐	☐	☐	☐
Aandachtig	☐	☐	☐	☐	☐
Actief	☐	☐	☐	☐	☐

Geef aan welk antwoord bij u het best van toepassing is.

	Nooit waar	Bijna nooit waar	Zelden waar	Soms waar	Dikwijls waar	Bijna altijd waar
Het is oké als ik me iets onaangenaams herinner.	☐	☐	☐	☐	☐	☐
Mijn pijnlijke ervaringen en herinneringen maken het me moeilijk om een waardevol leven te leiden.	☐	☐	☐	☐	☐	☐
Ik ben bang voor mijn gevoelens.	☐	☐	☐	☐	☐	☐
Ik maak me zorgen dat ik niet in staat ben mijn zorgen en gevoelens onder controle te houden.	☐	☐	☐	☐	☐	☐
Mijn pijnlijke herinneringen verhinderen mij een bevredigend leven te leiden.	☐	☐	☐	☐	☐	☐
Ik heb controle over mijn leven.	☐	☐	☐	☐	☐	☐
Emoties veroorzaken problemen in mijn leven.	☐	☐	☐	☐	☐	☐
Het lijkt erop dat de meeste mensen meer controle over hun leven hebben dan ik.	☐	☐	☐	☐	☐	☐
Zorgen staan mijn succes in de weg.	☐	☐	☐	☐	☐	☐
Mijn gedachten en gevoelens staan de manier waarop ik wil leven niet in de weg.	☐	☐	☐	☐	☐	☐

De volgende vragen gaan over 'waardegericht leven'. Waarden zijn de keuzen die we maken over hoe we ons leven willen leiden. Dit betekent dat je bepaalt wat je belangrijk vindt in je leven, wat voor jou het leven de moeite waard maakt en je inspireert. De vraag die je je hierbij stelt is: wat wil ik van het leven? Wat vind ik belangrijk en wat voor een persoon wil ik zijn? Deze vragen gaan over het kennen van dergelijke waarden en leven naar die waarden.

Geef aan in welke mate u het eens bent met elk van de onderstaande stellingen:

	Helemaal niet mee eens	Niet mee eens	Neutraal	Mee eens	Helemaal mee eens
Ik heb waarden die mijn leven meer betekenis geven.	☐	☐	☐	☐	☐
Ik weet wat mij inspireert in het leven.	☐	☐	☐	☐	☐
Ik heb belangrijke waarden om naar te leven.	☐	☐	☐	☐	☐
Ik heb een belangrijk idee van wat ik met mijn leven zou willen doen.	☐	☐	☐	☐	☐
Ik maak keuzes op basis van mijn waarden, ook wanneer dat spanning geeft.	☐	☐	☐	☐	☐
Ik weet hoe ik mijn leven wil leiden.	☐	☐	☐	☐	☐
Ik weet wat ik met mijn leven wil doen.	☐	☐	☐	☐	☐
Ik vind dat mijn gedrag echt mijn waarden weerspiegelt.	☐	☐	☐	☐	☐
Ik vind dat mijn gedrag past bij mijn persoonlijke behoeften en verlangens.	☐	☐	☐	☐	☐
Mijn emoties weerhouden mij niet om te doen wat ik belangrijk vind.	☐	☐	☐	☐	☐
Ik leef, zoals ik altijd zou willen leven.	☐	☐	☐	☐	☐

Geef aan in welke mate u het eens bent met elk van de onderstaande stellingen:

	Helemaal niet mee eens	Niet mee eens	Neutraal	Mee eens	Helemaal mee eens
Ik ben tevreden over hoe ik mijn leven leid.	☐	☐	☐	☐	☐
Er is niets dat mij tegenhoudt om te doen wat ik echt belangrijk vind.	☐	☐	☐	☐	☐
Ik vind dat ik op dit moment voluit leef.	☐	☐	☐	☐	☐
Ik kom toe aan dingen die belangrijk voor me zijn.	☐	☐	☐	☐	☐
Ik voel dat ik volledig leef.	☐	☐	☐	☐	☐

Dit is het einde van het vragenlijstonderzoek. Eventuele opmerkingen kunt u hieronder kwijt. Als u graag op de hoogte gehouden wilt worden van onze onderzoeksresultaten kunt u hier uw e-mailadres of contactgegevens opschrijven.

Hartelijk bedankt voor uw medewerking!

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