Fatigue in rheumatoid arthritis (RA): the role of illness perceptions and coping – a qualitative study

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ABSTRACT (Dutch)

Inleiding: Naast pijn ervaren patiënten met rheumatoide artritis (RA) veelal vermoeidheid als symptoom. Opmerkelijk is dat er individuele verschillen in ervaren ernst/impact van vermoeidheid onder RA patiënten bestaan. Daarom was het doel van dit onderzoek verder inzicht te krijgen in verschillen tussen meer en minder moeë RA patiënten door de relatie tussen ziektepercepties (incl. zelfeffectiviteits overtuigingen), coping gedrag en waargenomen ernst/impact van vermoeidheid te bestuderen.

Methode: 14 patiënten namen deel aan de studie. Door het gebruik van semigestructureerde diepte-interviews werd informatie over coping gedrag en ziektepercepties verzameld. De ernst/impact van vermoeidheid werd gemeten met de BRAF-MDQ. Met een interpretatieve fenomenologische analyse aanpak werd een gemengd top-down en bottom-up codeerschema genereert. De gegevens werden geanalyseerd volgens dit schema in ATLASti. Op basis van de mediaan van de totaal score van de BRAF-MDQ werden de patiënten in twee groepen gesplitst (meer/minder vermoeid). Groep trends werden in de data geïdentificeerd door de interviews van elke groep voor vereenkomsten en verschillen in ziektepercepties en coping gedrag te vergelijken.

Resultaten: De twee groepen verschilden van elkaar in hun ziekte percepties over vermoeidheid. Allebei rapporteerden een groot aantal en verscheidenheid van fysieke vermoeidheidssymptomen. Anders dan minder moeë patiënten, meldden meer vermoeide patiënten daarnaast vele en verschillende emotionele symptomen, hadden ze de neiging om tussen verschillende typen van vermoeidheid te onderscheiden en namen ze meer en ernstige gevolgen waar. Bovendien rapporteerden de meeste meer vermoeide patiënten chronische tijdlijnen en oorzaken, terwijl degene van de meeste minder moeë patiënten episodisch waren. Beide groepen hadden sterke zelfeffectiviteits overtuigingen, maar meer vermoeide patiënten ervoeren vaak een feitelijke gebrek aan controle vanwege hun vermoeidheid. Beide groepen hadden een breed repertoire van coping-strategieën. Echter, was de meer vermoeide groep meer rigide, vertraagd en context-onafhankelijk in de toepassing ervan en had ze een algemene voorkeur voor het onderdrukken van vermoeidheidssymptomen. Hun beoordeling van repressie als effectief leek te wijten te zijn aan niet-gezondheid gerelateerde redenen. Vanwege een tendens naar adaptief coping gedrag vertegenwoordigden twee meer vermoeide patiënten bijzondere gevallen.

Discussie: De resultaten van de analyses wijzen op het belang van psychologische factoren als het gaat om vermoeidheid in RA. Bovendien suggereren de bevindingen, dat het dynamisch samenspel van ziekte percepties en coping gedrag van essentieel belang is in de succesvolle aanpassing aan vermoeidheid. Het wordt dus aangeraden om in de ontwikkeling van interventies tegen vermoeidheid rekening te houden met zowel ziekte percepties als coping gedrag van RA patiënten. Het ontwikkelde heuristische model kan in toekomstig onderzoek als een bron voor hypothesen dienen. Bovendien lijkt het aan te raden de adaptiviteit van coping gedrag en de rol van het zelf concept van RA patiënten te bestuderen als het gaat om individuele verschillen in ernst/impact van vermoeidheid.

ABSTRACT (English)

Introduction: Besides pain, patients with rheumatoid arthritis (RA) commonly experience fatigue as a symptom. Remarkably, individual differences in felt severity/impact of fatigue exist among RA patients. Therefore the aim of this study was to further increase our understanding of differences between more and less tired RA patients by investigating the relationship between illness perceptions (incl. self-efficacy beliefs), coping and perceived severity/impact of RA fatigue.

Method: 14 patients participated in the study. By use of semi-structured in-depth interviews, information about coping and illness perceptions was gathered. The severity/impact of RA fatigue was measured with the BRAF-MDQ. An interpretative phenomenological analysis approach was used to generate a mixed top-down and bottom-up coding scheme. The data was analyzed according to this scheme in ATLASti. Next, based on the median of the total score of the BRAF-MDQ the patients were split into two groups (more/less tired). Group-trends in the data were identified by comparing the interviews of each group for similarities and differences in illness perceptions and coping behavior.

Results: The two groups differed in their cognitive representation of fatigue. Both of them reported a great number and variety of physical symptoms. In contrast to less tired patients, more tired patients also reported more and various emotional symptoms, tended to distinguish between different types of fatigue and tended to perceive more and severe consequences. Moreover, they mostly held chronic timeline and causal beliefs, while those of the less tired patients tended to be episodic. Interestingly, both groups had strong self-efficacy beliefs but the more tired group frequently experienced an actual lack of control due to their fatigue. Both groups had a broad repertoire of coping strategies. However, the more tired group was more rigid, delayed, and context-independent in the application of coping strategies, and had a general preference for repressing symptoms associated with fatigue. Their appraisal of repression as effective seemed to be due to non-health related reasons. Two of the more tired patients represented special cases, in a sense that they were tired despite a tendency towards adaptive coping.

Discussion: Findings of the analysis point towards the importance of psychological factors when it comes to RA fatigue. Concerning the successful adaption to fatigue, the findings suggest that it is the dynamic interplay between illness perceptions and coping behavior, which is important. This puts forth the advice of taking into account RA patient’s illness perceptions as well as coping behavior when developing interventions for fatigue. The developed heuristical model can serve as a source for hypothesis for future research. In addition, future research should examine the adaptability/maladaptability of coping behavior and the role of RA patients´ self-concepts with reference to individual differences in felt severity/impact of fatigue.

INTRODUCTION

Rheumatoid arthritis (RA) - a common chronic disease

Chronic diseases are one of the main burdens the population of developed countries recently faces. These are diseases of long duration, often incurable, which people mostly struggle with all their lives (Goodheart & Lansing, 1997). One common chronic disease is rheumatoid arthritis.

Rheumatoid arthritis (RA) is a chronic, progressive, autoimmune disease characterized by an inflammation of the synovial membrane (synovium) in the joints (Kvien, Scherer & Burmester, 2009). Inflammation causes damage to articular and periarticular tissues, deformation and dysfunction of multiple joints.

RA affects 0.5 to 1.0 percent of adults in developed countries, it is more frequent in women (3:1), and prevalence rises with age (Wright, 2015). Typically, the disease onset is between the age of 55 and 65 but the incidence rate increases when people get older (Doran et al. 2002).

While the disease progresses, patients face numerous somatic, psychological, and social dysfunctions. For example, 1/3 of the patients become disabled and often have to give up their job (Verbrugge & Juarez, 2006). Additionally, in estimated 14 to 62 percent of RA patients' depression occurs (Katz & Yelin, 1993). Next to symptoms such as pain, stiffness, eventually fixed deformations, and functional limitations – one substantial reported symptom of RA patients is fatigue (Kvien, Scherer & Burmester, 2009). Although the symptoms are irreversible effective treatment, can cause remission of symptoms and enable normal functioning (Kvien, Scherer & Burmester, 2009).

Fatigue in RA – importance, definition, impact and treatment

According to RA patients fatigue is a common, important, and pervasive symptom (Wolfe, Hawley & Wilson, 1996). In line with this finding, Stebbings and Treharne (2010) conducted a survey among RA patients, which revealed that an estimated 40 to 80 percent of all RA patients suffer from substantial fatigue. RA patients even perceive this symptom as important as pain and as having a marked impact on the quality of their life (Hewlett et al., 2005; Suurmeijer et al., 2001; Rupp et al., 2004). Moreover, RA patients experience it as a pervasive symptom, which is difficult to deal with and hard to improve (Repping-Wuts et al., 2003). Overall, fatigue seems to be of major concern to many RA patients. Therefore, it is not surprising that international consensus was reached that fatigue should now be evaluated in all RA clinical trials (Kirwan et al., 2007).

By now, there is no internationally accepted definition of fatigue (Hewlett, Hehir & Kirwan, 2007). This lack of definition is partly due to the subjective nature of the concept. The subjective nature is also part of RA fatigue's definition by Dittner et al. (2004) "*fatigue is an essentially subjective experience that can be described as extreme and persistent tiredness, weakness, or exhaustion – mental, physical or both*." Moreover, qualitative studies revealed that RA patients experience it as an annoying, multi-dimensional persistent symptom with far-reaching consequences on daily life (Hewlett, et al., 2005). Regarding the subjective nature of the concept, it is not surprising that among RA patients there can be found different types of fatigue, and individual as well as intra-individual differences in severity, frequency, and duration of fatigue (Nikolaus, Bode, Taal & van de Laar, 2010).

RA fatigue impacts on the person's whole life. It has physical, emotional, social, as well as cognitive consequences. For example, it often makes the fulfilling of normal tasks at work, as well as at home difficult (Hewlett et al., 2005) and it is an important predictor of absenteeism and early retirement (De Croon et al., 2005). Furthermore, it has been found that people who perceive fatigue as having a huge impact on their life also report higher scores of fatigue severity (Katz, 1998). This is especially the case with chronic fatigue. Hence, the main problem with RA fatigue is that it becomes a chronic state if it is not resolved (Repping-Wuts, Fransen, van Achterberg, Bleijenberg & van Riel, 2007). Piper (1993) defined chronic fatigue as following, "*Chronic fatigue is perceived as unpleasant, unusual, abnormal or excessive whole-body tiredness, disproportionate to or unrelated to activity of exertion and present for more than one month. Chronic fatigue is constant or recurrent, it is not dispelled easily by sleep or rest and it can have profound negative impact on the person's quality of life*."

Given the profound impact of fatigue on RA patient's whole life, good treatment is needed. Although pharmacological treatments have been shown to reduce the impact of RA on patients' lives, their effect on fatigue is still limited (Chauffier et al., 2012). Some evidence exists for the effectiveness of non-pharmacological intervention. For example, physical activity, psychosocial interventions, patient education, and self-management programs have been shown to have positive effects on self-reported fatigue in adults with RA (Cramp et al., 2013; Iversen, Hammond & Betteridge, 2010). However, effective evidence-based treatments are still rare. In order to be able to improve future treatments more insight is needed into the etiology of RA fatigue.

Multicausality of RA fatigue

Little is known about the etiology of fatigue in RA (Repping-Wuts, van Riel & van Achterberg, 2009). Several factors already have been identified, which are expected to account for some of the individual differences in felt severity and impact of fatigue among people suffering from RA – such as illness perceptions, self-efficacy beliefs, and coping (Stebbings & Treharne, 2010).

Fatigue is likely to have complex, multi-causal pathways comprising varying combinations of physical, psychological, and environmental factors (Hewlett, Nicklin & Treharne, 2008; Pollard et al., 2006; Treharne et al., 2008; Hewlett et al., 2011).

Hewlett et al. (2011) developed a conceptual model for fatigue in RA, which reflects the dynamic interrelationships between fatigue and physical, psychological, and environmental factors. Their model consists of three factors: (1) '*RA*' which contains disease processes; (2) '*cognitive behavioral*', which includes thoughts, feelings, and behaviors; and (3) '*personal*' representing personal issues in the life of the patient. All factors included in the model are assumed to have the potential to predispose to fatigue, precipitate a specific fatigue episode, or perpetuate existing fatigue. However, as long as evidence for the hypothesized relationships is lacking, their model remains on a heuristic level.

A systematic review by Nikolaus et al. (2013) provided an overview of possible causes and consequences of fatigue in RA. They only found partial support for the proposed relationships of the model by Hewlett et al. (2011).

While the proposed relationship between fatigue and variables on the RA dimensions of disability, pain, and sleep matched the literature, the proposed relationships between fatigue and the illness-related aspects such as inflammation did not (Nikolaus et al., 2013). Thus, it becomes clear that disease-related factors are not the full answer to questions such as why do some people suffering from RA feel more fatigued than others.

In the systematic review of Nikolaus et al. (2013) strong support was found regarding the dimension '*cognitive behavioral*' of the model for factors such as responsibilities, social support and depression. Support was also found for the existence of relationships between fatigue and other elements of this dimension such as illness beliefs, self-efficacy beliefs, and coping behavior in the literature. However, only on a few studies provided evidence for '*cognitive behavioral factors'*, making it difficult to draw clear conclusions. The same was true for factors of the dimension '*personal*'.

A closer examination of all potential factors represented in the conceptual model of RA fatigue would be beyond the scope of this study. Given the need for further research on factors of the '*cognitive behavioral dimension*', three psychological factors have been selected. In the following the illness cognitions, self-efficacy beliefs and coping behavior will be examined in more detail.

Illness representations (including self-efficacy beliefs) and coping behavior

Leventhal's et al. (1992) self-regulation model guides research on illness perceptions. In the context of this model illness perceptions (or illness representations) are patients´ own implicit model of their illness, based on different sources of information such as symptom perception and information from other people (Leventhal, Nerenz & Purse, 1984). According to the self-regulation model, people build cognitive representations of the illness/symptom in order to make sense of their illness experience. These cognitive representations determine emotional responses to the illness, drive attempts to cope with the illness/symptom, and thereby influence health outcomes such as perceived severity/impact of fatigue in RA (Leventhal, Brissette, & Leventhal, 2003). The self-regulation processes are dynamic – as feedback from appraisals of coping efforts influence cognitive representations, emotional responses, and future coping behavior (Leventhal et al., 1984, 1992).

While trying to make sense of the problem a cognitive representation of one's illness is constructed according to five core dimensions (Leventhal, Nerenz & Purse, 1984; Petrie & Weinman, 1997): (1) *Identity* (beliefs about the label placed on fatigue and the associated symptoms); (2) *Consequences* (beliefs about the severity of fatigue and its likely impact on physical, social and psychological functioning); (3) *Perceived causes of the illness* (beliefs concerning how one gets fatigued); (4) *Time line* (beliefs about its duration and its characteristic course); and (5) *Curability and controllability* (beliefs about preventability, curability and controllability of fatigue). Given that self-efficacy can be considered a perception of control, self-efficacy and the control/curability dimension of the self-regulation model can be viewed as measuring the same construct (Bandura, 1977).

In the context of the social-cognitive theory by Bandura (1986), perceived self-efficacy is defined as "*people's judgement of their capabilities to organize and execute courses of action required to attain designated types of performance. It is concerned not with the skill one has, but with the judgement of what one can do with whatever skill one possesses*" (Bandura, 1986, p.391). People's beliefs about their capabilities do not have to be in line with their objective capabilities. If this is the case, one speaks about self-inefficacious thinking, which creates discrepancies between knowledge and action. In other words, despite knowing what to do and having the required skills to do it, people fail to manage situations effectively (Rimal, 2000).

To my best knowledge, by today seven studies on RA patient's illness perceptions about fatigue have been conducted, whereby five of them solely investigated RA patient's self-efficacy beliefs. Two longitudinal studies applied the self-regulation model. They found that beliefs held about one's disease predict the severity of fatigue in RA patients after one year. RA patients who perceived RA to have severe consequences at baseline (Scharloo et al, 1999; Treharne et al., 2008) as well as perceived fatigue as uncontrollable (Treharne et al., 2008) suffered from more severe fatigue a year later.

The five studies on efficacy beliefs about fatigue came to different conclusions. With regard to fatigue in RA a longitudinal cohort study conducted by Brekke, Hjortdahl, and Kvien (2001, 2003) found lower arthritis self-efficacy to be a predictor of greater fatigue up to 5 years later while controlling for baseline fatigue. This is in line with the findings of Treharne et al. (2008). Additional support for this relationship comes from three cross-sectional studies (van Hoogemoed, Fransen, Bleijenberg & van Riel, 2010; Riemsma et al., 1998; Jump et al., 2004). In contrast, one cross-sectional study did not find any support for a relationship between self-efficacy perceptions and severity/impact of RA fatigue (Huyser et al., 1998).

Coping

Another psychological factor that has been investigated with respect to RA fatigue is coping. According to the general cognitive model of coping with stress of Lazarus and Folkman (1984) coping is defined as a "*process that involves a persons' cognitive and behavioral efforts (coping strategies) to manage psychological stress related to the challenges and losses the person experiences because of illness*." Thus, coping involves a cognitive assessment of the stressful situation and some one's own capabilities to cope with this situation.

Coping is a central aspect of Leventhal's self-regulation model. According to the self-regulation model both, someone's' coping efforts and the appraisal of their effectiveness, are guided by illness representations (Aujoulat, Marcolongo, Bonadiman & Deccache, 2008). Thus, depending on the beliefs people have about a symptom, they will behave differently.

In research on the link between illness perceptions, coping and health outcomes Lazarus and Folkman's (1984) general cognitive model of coping with stress is often used because it was found to be compatible with the self-regulation model of illness (Park, 1994). This kind of research makes a distinction between problem-focused and emotion-focused coping (Folkman & Lazarus, 1980). Emotion-focused coping involves changing one's own emotional reaction towards the stressor. An example is the escape-avoidance coping strategy wishful thinking. In contrast, problem-focused coping involves trying to reduce or eliminate the source of the stress.

Coping strategies can be adaptive or maladaptive. Contrary to maladaptive coping, a coping strategy is adaptive, if it is effective in improving adjustment to illness (Lazarus & Folkman, 1984). In general, a broad repertoire consisting of both problem- and emotion-focused strategies provides a good starting point for adaptive coping. However, to be effective a coping strategy should be matched on the particular demands of the situation at hand (Zeidner & Saklofske, 1996). Moreover, greater flexibility and a better timing in the use of coping strategies increases the likelihood, while a more restricted or rigid coping decreases the likelihood of successful adaption to illness (Miller, 1990).

Much research on coping with stressful situations determined strategies that encourage positive adaptation to the disease and some that impede it. However, when it comes to fatigue in RA a search of the literature solely revealed three studies on this topic. One cross-sectional study by van Hoogemoed et al. (2010) revealed that avoidant coping (operationalized as wishful thinking) is associated with higher levels of self-reported severity of fatigue in RA patients. Of special interest, two longitudinal studies investigated whether coping behavior mediated the effect of illness perception on perceived severity/impact of fatigue after one year among RA patients by applying the self-regulation model (Scharloo et al. 1999; Treharne et al., 2008). In line with the findings of van Hoogemoed et al. (2010), the longitudinal study of Scharloo et al. (1999) revealed the use of avoidant coping (operationalized as wishful thinking) to be a mediating factor between illness representations and disease outcome. However, in the longitudinal study of Treharne et al. (2008) avoidant coping was not a mediating factor. This profound discrepancy in their findings reflects the two different views in illness perception research. Some assume coping to be a factor linking illness perceptions and outcome, while others consider it to be less important, stating a direct link between illness perceptions and outcome (Petrie & Pennebaker, 2008). With respect to RA fatigue, evidence for both views can be found.

To sum up, based on the findings on illness perceptions, self-efficacy beliefs and coping, several conclusions can be reached. First, illness perceptions (especially self-efficacy beliefs) and coping behavior seem to play a role in the worsening of RA fatigue. Second, illness perceptions and coping behavior can be assumed to account for some of the individual differences in perceived severity/impact of fatigue in RA. This leads to the conclusion that additional research on the relationship between illness perceptions (including self-efficacy beliefs) and coping behavior among RA patients seems to be vital. These general conclusions are represented in Box 1.

Box 1. *General conclusions*

1. Illness perceptions (including self-efficacy beliefs) and coping behavior seem to play a role in the worsening of RA fatigue.
2. Illness perceptions (including self-efficacy beliefs) and coping behavior can be assumed to account for some of the individual differences in felt severity/impact of fatigue in RA.

Aim of this study

In their review, Nikolaus et al. (2013) concluded that additional research on the relationship between psychological factors and individual differences in the perceived severity/impact of RA fatigue is needed. Doing so might help to provide answers to questions such as "*Why do some RA patients suffer more from fatigue than others*?" and "*Why do some RA patients develop chronic fatigue while others do not*?" and thereby might inform the development of effective interventions for RA fatigue.

Based on previous research findings it has been concluded (see Box 1.) that a closer investigation of RA patient's illness perceptions and coping behavior might help to understand individual differences in the adaptive process to RA fatigue and therefore additional research on this topic seemed to be vital.

The aim of this study was to increase our understanding of differences between more and less tired RA patients by investigating the relationship between illness perceptions (incl. self-efficacy beliefs), coping with and the perceived severity/impact of RA fatigue.

To my best knowledge, by today two quantitative studies investigated the relationship between illness cognitions, coping behavior, and the perceived impact/severity of RA fatigue (Treharne et al., 2008; Scharloo et al., 1999). Given that both studies had used quantitative methods of investigation, this study is the first qualitative study. Furthermore, it is the first study on this topic conducted in Germany.

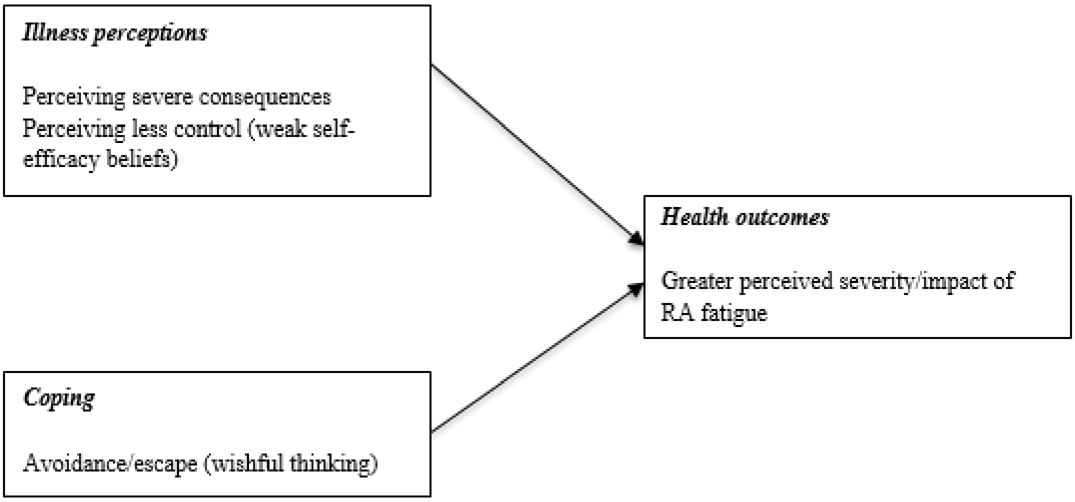
A qualitative method of investigation can complement quantitative studies in a number of ways (Pope, 1995). First, previous quantitative findings can be validated with a different methodology; second, the design of future questionnaires can benefit from more detailed descriptions of the phenomena under investigation; third, important idiosyncrasies in the meanings that words have for patients can be revealed; and fourth, hypotheses can be generated for future testing in quantitative investigations.

To sum up, the aim of this study was to shed light on differences between more and less tired RA patients by investigating the relationship between (1) the cognitive representations German RA patients hold about their fatigue, (2) their coping efforts to manage their fatigue and (3) the perceived severity/impact of RA fatigue. Regarding this aim, the following research questions have been chosen:

1. What illness perceptions do RA patients hold about fatigue?
2. How do RA patients cope with their fatigue?
3. How do the patients themselves perceive the relationship between felt severity/impact of RA fatigue, their illness perceptions, and coping efforts? (Do they perceive such a relationship after all?)

With respect to the results of this study, the researcher had several expectations about the relationship between illness perceptions, coping efforts, and the perceived severity/impact of RA fatigue. More tired patients (greater perceived severity/impact of RA fatigue) were assumed to (1) perceive severe consequences, (2) perceiving less control and (3) make use of wishful thinking when it comes to RA fatigue. The three hypotheses about possible relationships between the three constructs under investigation are depicted in figure one.

Figure 1. *Heuristical model of the relationships between the three constructs*



METHOD

Design

A qualitative methodology of semi-structured in-depth interviews was used (Kvale, 1996). By confidential contract with volunteer helpers of the Deutsche Rheuma Liga, Gronau, Germany, twenty patients with rheumatoid Arthritis were invited to participate in this study. The patients were contacted via an official letter from the Deutsche Rheuma Liga including a flyer (see Appendix III). After one week, they were again contacted by telephone and with interested patients an appointment was made. The interviews on average lasted 1 ½ hours and took place at the patient's home or at a branch office of the Deutsche Rheuma Liga in Germany from April 2015 to March 2015. Prior to the interviews an informed consent was obtained from the patients and they were informed about their rights to withdraw from the study (see Appendix II). In addition, the patients filled in the German version of the BRAF MDQ at the beginning of the interviews in order to assess the perceived severity of RA fatigue and its perceived impact on different domains of the patient's life (can be downloaded http://www.uwe.ac.uk). The study was approved by the Ethics Committee of the faculty of Behavioral Sciences from the University of Twente, in the Netherlands.

Sample

Sixteen patients (1 man and 15 women) agreed to be interviewed. Two out of the 15 female patients were excluded from the study, because their representativeness for the study was doubted. One patient stated that her fatigue was due to a depression and showed symptoms of a depression during the interview, and the other patient stated that she did not feel tired and had no experience with RA fatigue. Thus, they seemed to have no experience with RA fatigue, or their description of RA fatigue might probably be biased due to comorbidity. The mean age of the final sample (N=14) was 54 years (SD=15, 5). The age ranged from 22 years to 79 years. The range of RA duration was 1 year to 43 years with a mean of 18 years (SD=12, 53). With respect to their housing and relationship situation, only two patients lived alone and more than half of them had a partner at that moment. This sample also varied greatly in educational level and career (from secondary education to university degree and from office cleaners to engineer). Seven patients were retired (invalidity or old age pension). Two stayed at home at that moment and five patients were employed or students. Most of them frequently consulted a rheumatologist and took medication on a regular basis. Only four patients reported no comorbidities and most of the patients suffered from sleeping difficulties. The results of the total and sub-scores of the BRAF-MDQ are shown in Table 1. The total score of the BRAF MDQ indicated the perceived overall severity of RA fatigue, while the sub scales indicated the perceived impact of RA fatigue on different areas of the patient's life. The total score ranged from 4 to 58 on a scale of 0-70 (Mean=25,57;

SD=13,25). Regarding data from a previous study by Nicklin et al. (2010) the sample of the current study suffered from less severe fatigue (Previous study: Mean = 38,4; SD=13,7). The higher mean in the previous study seemed to be due to a pre-selection of RA patients. Only patients rating their fatigue ≥ 5 on a visual analog scale were recruited. The sample of the current study therefore showed a greater variability in perceived severity/impact of RA fatigue. Concluding, except for gender, the sample varied greatly in demographics and perceived severity/impact of RA fatigue, making it possible to obtain a variety of experiences in living with RA fatigue and suitable for the examination of individual differences.

Table 1. *Results of the BRAF-MDQ*

Scores	Mean	SD	Median	Range	Scale
Physical	11,14	4,32	11	2-17	0-22
Cognitive	5,07	3,77	5	0-14	0-15
Living	6,14	5,04	4	0-18	0-21
Emotional	3,21	2,96	3	0-10	0-12
Total score	25,57	13,25	24,5	4-58	0-70

Interviews

A hierarchical interview scheme was used, which covered the main topics and consisted of open questions and several closed questions for further clarification. Main topics were: (1) general information about the patient; (2) general information regarding the rheumatoid arthritis; (3) illness perceptions about RA fatigue; (4) coping with RA fatigue; and (5) patients own view on a possible connection between felt severity/impact of RA fatigue, illness perceptions and coping. This interview scheme is partly – except the questions about the connection – based on previous interview studies (O'Neill, 2002; Green, Payne & Barnitt, 2004, Power, et al., 2008). A comprehensive interview scheme can be found in Appendix I.

Box 2. *Overview of the interview topics*

(1) General information: patient	E.g. How old are you? What is your employment status at the moment?
(2) General information: RA	E.g. When was your RA diagnosed?
(3) Illness perceptions	
Identity	E.g. How would you describe your fatigue experience?
Cause	E.g. What do you think caused your fatigue?

Consequences	E.g. How has fatigue affected your life?
Time line	E.g. Would you describe your fatigue as chronic, episodic or acute? Or something else?
Control/cure	E.g. Do you think you can influence your fatigue?
(4) Coping	E.g. How do you cope with your fatigue?
(5) Connection	E.g. Some people think that a connection exists between the felt severity/impact of fatigue, the way one thinks about one's fatigue and the way one copes with one's fatigue. What do you think?

Data analysis

Before reading the interviews, appropriate precautions have been taken to avoid possible biases during the data analysis phase. Reading studies about the topic under investigation clearly left its mark, therefore expectation-free research is impossible. Unconscious beliefs can lead to biased results, for example, the researcher only attends to the information which fits his/her hypothesis and ignores contradicting information (Ashworth & Lucas, 2000). In order to reduce the influence of unconscious beliefs one must bring them to the level of consciousness. This can be done by being explicit about one's beliefs. The hypotheses of the researcher were written down and are depicted in figure 1 above.

The sample size was adequate to reach saturation – in a sense that after thoroughly reading and analyzing seven transcripts the remaining interviews did not reveal new themes concerning the constructs under investigation. Citations from the patients were used to illustrate the findings. The translation from German to English was done by a bachelor degree English student and reviewed by the researcher.

Initially, with an interpretative phenomenological analysis approach by Smith, Jarman & Osborn (1999) a mixed top-down and bottom-up coding scheme was generated. The data was coded with help of ATLASti software. A top-down approach was used through which the text was coded according to the elements of (1) Leventhal's et al. (1992) self-regulation model (identity, cause, time-line, consequences and cure/controllability) and (2) patients answers concerning connection between illness perceptions, coping and the felt severity/impact of fatigue (Yes, no or partly). Furthermore, (3) Folkman's and Lazarus' (1980) classification of emotion- and problem-focused coping strategies was used to label the described coping efforts of the patients. The adaptability/maladaptability of the coping strategies (Zeidner & Saklofske, 1996; Miller, 1990) was examined by searching for quotes that indicate timing, flexibility/rigidity and situation-dependency. In addition, (4) the dimensions of the BRAF-MDQ were used as subcategories to label statements that indicated beliefs about consequences. Therefore, the labels (1) '*physical*', (2) '*cognitive*', (3) '*living*', and (4) '*emotion*' were used to classifythe perceived consequences of RA fatigue according to their impact on different areas of the patient's life. The self-regulation model framework, the classification of the patients' answers on the connection question, the framework of Folkman and Lazarus (1980) and the criteria for adaptive coping accounted for the majority of the data. Furthermore, the sub-dimensions of the BRAF-MDQ could account for most of the reported beliefs about consequences during the interviews. In the next step, the data that could not be explained by top-down coding was used to form new subcategories through axial coding (bottom up). During this step, the subcategory '*positive consequences*' was made to account for beliefs about positive consequences of RA fatigue. Moreover, the subcategory '*appraisal of the effectiveness of coping'* was included as a distinct subcategory of coping. By use of the resulting mixed bottom-up and top-down coding scheme the interviews were again top-down coded in ATLASti and the coding scheme could account for the majority of the data. The final coding scheme can be found in appendix IV.

In order to shed light on the differences between more and less tired RA patients regarding their illness perceptions and coping efforts, the patients were categorized into two groups based on the felt severity/impact of RA fatigue. Therefore, the sample's median of the total score (Median =24,5) of the BRAF-MDQ, which indicates felt severity/impact of RA, was used to split the patients into two equal groups. Patients scoring higher than the mean (N=7) were classified as '*more tired*' and patients scoring lower than the mean (N=7) were classified as '*less tired*'. Then it was searched for group-trends in the data (more tired Vs. less tired group) by comparing the interviews of each group for similarities and differences in illness perceptions, coping behavior, and their answers on the question about a possible connection between the constructs under investigation. Trends are statements that are heard frequently from a group (Madrigal & McClain, 2012). The differences and similarities between '*more tired*' and '*less tired*' patients were presented per group.

RESULTS

1. *What illness perceptions do RA patients hold about fatigue?*

Identity

The cognitive dimension '*identity*' includes perceived symptoms such as lack of energy or listlessness and the label placed on fatigue. The reported physical and emotional symptoms are shown below in table 2.

More tired patients tended to report more physical *and* emotional symptoms during the interview and they showed a tendency towards distinguishing between different types of fatigue. They perceived RA fatigue as a special kind of fatigue due to its differences to normal tiredness. The distinction from normal tiredness was made based on one or more of the following criteria: they experienced RA fatigue as more severe, of worse sleep quality, not improvable by sleeping, without cause, as a physical and psychological burden, and as unpredictable. Some of these criteria will be described in more detail with respect to other cognitive dimensions.

"How can I best describe it? It's standard. You get up in the morning and you're just tired. The whole day it doesn't go away. Yes, for me it has become a standard feeling. I can't describe it any different. You're always just tired." (Patient 15)

Most of the more tired patients experienced a mixture of the following two types of severe fatigue. The label '*leaden tiredness*' was used by some patients to describe a severe physical type of fatigue. It was associated with a strong need for sleep/rest, a feeling of heaviness in various parts of the body such as eyelids or legs, feebleness/exhaustion and sometimes headaches.

"Often it comes like a bolt from the blue. Really, I'm feeling good and suddenly I realize that I am getting tired. And then it's really difficult for me to keep my eyes open. That's what I always notice at those moments. Then I always say – like a leaden tiredness. And if I have the opportunity to – you don't always have it – but if I have the opportunity to just lie down, then I fall asleep right away. That's how I would describe it." (Patient 10)

Additionally, one patient explicitly referred to a type of severe fatigue that was experienced more emotionally as '*faint-hearted tiredness*'. It was accompanied by emotional symptoms such as listlessness/lack of drive, more or less severe forms of emotional distress and sometimes fears, a feeling of overburden and a strong need to seal oneself off.

"So faint-heartedly tired. I would say so. You really don't have the power and you know 'you can't achieve what your environment asks from you' [...] and then, sometimes it's just all too much. And

then uh, then I have the feeling of – please can't you just leave me alone. Then I just want to, yes, if I could just sit down somewhere, just resting your legs for a moment, not seeing or hearing anymore. Because sometimes, it just gets over my head. And then, eh, you also feel exhaustion, discouragement and you sometimes think "Can you achieve it all?" and "How shall you manage this again?" and "I'm not really able at this moment". And I would just like to run away from it. Well, this feeling you sometimes have." (Patient 4)

In contrast, most of the less tired patients did not differentiate between types of fatigue. Rather, they assumed RA fatigue to be a more intense form of '*normal tiredness*', which to their understanding indicated a need for rest or sleep. Misleadingly, they sometimes described the experience of heightened normal tiredness as '*leaden tiredness*'. However, contrary to the more tired patients they generally associated RA fatigue with physical symptoms and less or even no emotional symptoms. If emotional symptoms were reported, it concerned less severe ones such as listlessness or annoyance.

"Actually that's not how it is [that there are different forms of fatigue], the frequency and how intense it is – yes, that's true. It's during periods of acute rheumatism, when it's more intense. But there is no difference in the feeling itself. [...] Well you sometimes lack the energy. It's just that you are really tired, for example in the evening. I can just fall asleep immediately. In the evening I get a leaden tiredness and I can fall asleep immediately. And if I don't get enough sleep, I realize it the next morning." (Patient 13)

Also, two patients among the less tired ones stated that they had experienced a mixture of these special types of fatigue in their past but now no longer perceived any difference between types of fatigue. This suggested that identity beliefs could possibly change over time.

And did you experience any difference in the past?

> *"Yes."*

And what kind of difference?

> *"One does not have much energy, you are listless, you sometimes just lay down on the couch and let the household be the household. The kids were still little, you were able to... you could not just lie down. Such is life." (Patient 12)*

Table 2. *Emotional and physical symptoms associated with RA fatigue*

Emotional symptoms	Physical symptoms

Listlessness/ Lack of drive	Strong need for sleep/rest
Feeling depressed/sad	Feebleness/Exhaustion/Lack of energy (physical)
Strong need to seal oneself off	Heaviness (especially eyes)
Fear/Panic	Headaches
No feelings/it’s normal	Sleeping difficulties
Annoyance	

Consequences

With respect to the perceived impact of RA fatigue on the patient’s life the subscales of the BRAF-MDQ were used as subcategories: (1) ‘*physical*’, (2) ‘*cognitive*’, (3) ‘*living*’, and (4) ‘*emotion*’. In addition, some patients stated that they perceived positive consequences, thus this was included as the additional subcategory (5) ‘*positive*’. All consequences that were reported during the interview are shown below in table 3.

Table 3. *Perceived consequences of RA fatigue*

Physical	**Living**	**Cognitive**	**Emotional**	**Positive**
Lack of physical energy, Restricted vitality, Pain	Social life: Affected social life, Restricted enjoyment/participation, Refusing invitations/requests, Inability to provide social support Daily life: Avoidance to make plans, Cancelling plans, Difficulties during work/other activities, Reduction in the quality/quantity of work output, Loss of time	Lack of concentration, Forgettfullness, Making mistakes	Decreased QoL, Emotional distress, Listlessness/lack of drive, Fear of being a burden/ of failure, Decreased self-esteem, Embarrassing, Irritability, Annoying, No specific feelings	Relaxing/ time for myself, Personal growth, Taking care of your limits/body

Overall, individual differences in beliefs about ‘*consequences*’ were congruent with individual differences in total and sub-scores of the BRAF-MDQ. In other words, the more tired group tended to reported more consequences of the subcategories ‘*physical*’, ‘*cognitive*’, ‘*living*’ and ‘*emotion*’ than the less tired group during the interview. Furthermore, the more tired patients perceived more severe consequences due to RA fatigue than did the less tired group – in the sense that more tired patients perceived RA fatigue as a physical and psychological burden due to its severity and negative impact on many areas of their life. In contrast, the less tired patients did not perceive RA fatigue as having severe consequences for their life.

In the following individual differences per subcategory will be described in more detail. The subcategory (1) ‘*physical*’ includes the patients´ perceived physical consequences. Regarding the scores on the questionnaire, it could be stated that the higher the ‘*physical*’ score of a patient, the more severe and the more often per week RA fatigue is experienced. In line with this, all but one patient (Patient 10) among the more tired patients (severity >5 and experienced 7 days a week) described their fatigue as chronic.

Most of the patients perceived (2) ‘*cognitive*’ consequences of RA fatigue such as decreased concentration, forgetfulness or making mistakes. In general, more tired patients experienced greater cognitive impact (‘*cognitive*’ sub-score above the median) – in the sense that they could name more cognitive consequences during the interview and assumed them to be of more serious impact. The patient with the highest score on this sub-scale illustrated it as following:

“When I drive from here to the city, then someone has to drive me, or go with me, otherwise I would fall asleep on the way. I already nodded off momentarily twice, it is unacceptable.” (Patient 15)

The subcategory (3) *‘living’* includes perceived consequences of RA fatigue on daily life as well as on social life. All patients reported some negative consequences of RA fatigue for their daily life such as difficulties in their work or daily activities, a reduction in their qualitative and quantitative work output, and a tendency to avoid making plans. However, more tired patients perceived consequences for daily life as more severe. This also became evident during the interview, as the following quote illustrates:

“It affects everything I do [fatigue]. Household, cooking, cleaning - everything. This is completely restricted.” (Patient 15)

In contrast, less tired patients rarely reported social impacts of RA fatigue, while more tired patients stated to experience negative impact of RA fatigue on their social life. During the interview, the more tired patients tended to report severe social consequences, such as restrictions in the fulfillment of their social and professional roles or frequently having to refuse invitations from friends. Due to this, they also tended to report more severe (4) '*emotional consequences'* of RA fatigue for their life, for example severe emotional distress. Feeling depressed and sad was in turn associated with a decreased quality of life – which mostly stemmed from perceived consequences of RA fatigue for fulfilling social roles.

"My husband is also someone who likes to celebrate and in general he wants me to join him. But I am not really able to take part consciously. You can't really say: I really enjoy this. So uh, what others find super cool and nice, I can't really join in. This joie de vivre other people have when sitting together in the evening and celebrating. Then I just think: you're so tired and so knackered, you would really like to lie down instead and you're not really enjoying it." (Patient 4)

In addition, fear of failure and the fear of becoming a burden to others due to RA fatigue was a central theme for those patients who perceived great impact of RA fatigue on their emotional and social lives.

"Because you're just a burden to others. They always have to show consideration for you. If now they would like to do something and I have to say 'No I don't have the energy anymore. That's not something you really want to do." (Patient 10)

"One just feels useless then. It's simply like, you have already accomplished something but others would have achieved even more than you. And you're already tired of what you've done." (Patient 4)

Both more and less tired patients commonly reported listlessness as emotional consequence. Listlessness seemed to be closely related to perceived consequences for social and daily life.

"Yes. Well, that's just, if you've made some plans, if you want to do something – but again you get this tiredness – then you just don't feel like doing so. Then you let it be, then you put if off, then you just postpone it." (Patient 9)

Most of the less tired patients perceived RA fatigue to be of less or zero emotional impact and stated that they had no specific feelings about their RA fatigue. Though they stated to have experienced negative emotional consequences in the past, they had undergone a process of adaption through which they learned to accept RA fatigue as a part of their life. If emotional consequences were named, they found them to be of low impact on their life because they got used to it. For example, they assumed RA fatigue to be embarrassing or annoying or found it to be a pity. This mirrored the findings on less tired patients concerning the '*identity*' dimension, where they reported few or zero emotional symptoms.

"Well I tried to ignore it [RA fatigue] for a long time. But I have accepted it and learned to live with it and try make the best out of it. But feelings? I have no specific feelings about it, of course would be nicer if it weren't so, but that's what it is for me now." (Patient 13)

Lastly, seven patients reported positive consequences of their RA fatigue such as taking care of your limits and being able to avoid overburden, time for yourself and being able to relax. Less as well as more tired patients reported positive consequences.

"You learn to listen to your body. I know just where my limits are and if one exceeds those limits it will affect your symptoms negatively. So as I have just said with my rhythm. If I ever get thrown out of it a bit, of course it can be adapted again, but I realize it because I am deprived of my activity then." (Patient 16)

Causes

Three themes related to the dimension '*causes*' were identified during the thematic analysis, namely (1) beliefs about the origin of RA fatigue, (2) beliefs about exacerbating factors and (3) conditions which serve as a buffer against RA fatigue and its possible negative impacts. All but one patient (Patient 8) could name multiple cause, exacerbating factors and conditions with a positive impact on fatigue. In addition, physical as well as psychological factors were assumed to play a role.

"That's a difference like day and night. If I had done something, had worked very much and then I fall asleep – then I know ah that's [the work] where it comes from! But when I simply sit down and do nothing, and then I suddenly fall asleep, then I haven't had done something you know?" (Patient 8)

Concerning the (1) underlying causes of RA fatigue, most frequently rheumatoid arthritis, and medications were reported. Most patients associated RA with a weakened immune system consuming more energy, which in turn lets them become more easily tired – especially in times of higher inflammatory activity.

"[...] Then I think, on the one hand, if the inflammation of my rheumatism is higher, that's a very clear factor. Since the body is inflamed and thus needs more energy and therefore you are exhausted and tired more easily." (Patient 13)

Another frequently reported cause was medication. On the one hand, fatigue was seen as a negative side effect of medication and on the other hand, the medication was seen as a cause of remission – improving RA and fatigue at the same time.

Seven patients believed that disturbances of their sleeping were an underlying cause of RA fatigue. In addition, some older patients assumed ageing to cause RA fatigue. Among them were the few patients who did not perceive any connection between their illness and RA fatigue. Next to RA, one patient assumed that in the past a depression might have played a causal role. The depression was seen as being linked to feelings of insufficiency concerning the decrease in performance, which in turn was caused by the restricted amount of energy. Thus, a depression could be seen as a cause as well as a consequence of RA fatigue.

"So I always feel downhearted. Sometimes I even think, you have a depression. That maybe that's the reason why you don't feel well, that's the reason you feel tired. That is, indeed, as if you're emotionally dull at those moments. Then one doesn't want to think of anything, then you just want to be left alone. [...] One just feels useless at those moments. It's simply like, you have already accomplished something but others would have achieved even more than you. And you're already tired of what you've done." (Patient 4)

The body's increased demand of energy also left the patient with less energy to spare on other things – and seemed to prepare the ground for increased fatigue and severe consequences such as stress, emotional distress, and lack of physical energy when facing exacerbating factors. Almost all patients believed having a job to be an exacerbating factor. On the one hand, having a job was believed to intensify fatigue due to the additional energy costs – which patient four suitably described as a "*double burden*." On the other hand, having a job was believed to increase fatigue due to a lack of spare time and therefore restricted possibility to organize your day and adapt successfully to fatigue.

"When I'm on internship or have a job. I believe that it [fatigue] will be more intense then. As a student you are flexible with your scheduling and you have more time than someone who has a job. So it could be, that it will become more intense then." (Patient 16)

In line with this statement, more autonomy at work was seen as a condition, which serves as a buffer against RA fatigue and its possible negative impacts. Besides having a job, daily activities were assumed to increase fatigue.

“Yes, of course, caused by work and normal activity that one performs. Be it in the garden, be it in the house. If you have to repair something or similar. Or if you want to run upstairs quickly, you're out of breath. Then you will also get tired.” (Patient 2)

In addition, a lack of social support was believed to increase fatigue. At the same time, the perception of social support was seen as a buffer against RA fatigue and its possible negative impacts.

“I really think this has to do with the psyche. If you are not feeling comfortable. If life doesn’t go as you would imagine – that the body reacts to it. And if feels good and if you have friends, gets treated nicely and then it’s better.” (Patient 12)

Some patients assumed focusing on negative things, worries and fears as an exacerbating factor. Also, mood and weather were believed to increase or decrease fatigue. If they were reported, they were commonly associated with each other.

“How you feel – there it also depends on. See, if the sun shines than you are - more motivated! And when the whether isn’t as nice as it should be, then you are more tired” (Patient 6)

Lastly, a bad physical condition was assumed give rise to increased fatigue. A bad physical condition was seen as lack of resources to compensate for the increased energy costs.

Timeline

All of the patients believed that their fatigue will stay with them for the rest of their lives and hoped that it will not get worse but stays the same. Thus, believing in the persistence of fatigue was independent of believes in a chronic (seven patients), episodic (six patients) or mixture of timeline believes (Patient 13).

“Yes, it mixes up a bit. It tends to be chronic, but it’s not the same every day. So it doesn’t show the same every day.” (Patient 13)

Episodic timeline beliefs were most frequently found among less tired patients, but some more tired patients assumed RA fatigue to be episodic, too. In both groups, episodic timeline beliefs were associated with beliefs about episodic causes, for example acute phases of their illness.

"One has good days. Probably really if this rheumatism just, I would say, yeah – is asleep a bit. Then you of course don't have it. If it is active [RA], then you also have this tiredness." (Patient 10)

In line with this, some less tired patients held chronic timeline beliefs, although chronic timeline beliefs were more common among more tired patients. Chronic timeline beliefs were associated with naming different but chronic causes for RA fatigue. For example, chronic RA or ageing. Due to the great variability of timeline beliefs within each group, timeline beliefs seemed to be a worse criterion for discriminating between more and less tired patients than perceiving severe consequences is.

Furthermore, perceiving severe consequences seemed to be a better criterion for discrimination than reporting RA fatigue to be unpredictable. Perceiving RA fatigue as unpredictable was found in combination with episodic (Patient 10 and 16) as well as chronic timeline believes (Patient 8). Three patients had in common that they differentiated between different types of fatigue. However, only the patient who perceived severe consequences (Patient 10) experienced a lack of control due to the unpredictability of her fatigue. Thus, unpredictability seemed to be associated with differentiating between different types of fatigue, but did not indicate a certain severity/impact of tiredness.

"That's often like the bolt from the blue. So really, I actually still feel very good and suddenly I realize I'm so tired. [...] But this tiredness it just comes ad hoc. Which is suddenly there and you can't influence it." (Patient 10)

Curability and controllability (including self-efficacy beliefs)

During the interview, all patients reported they were able to exercise some kind of control over their fatigue (self-efficacy beliefs). To clarify what the patients meant by '*some kind of control*' their answers to the question "*Have you felt you have less control in areas of your life because of fatigue?*" from the '*emotion*' sub-scale of the BRAF-MDQ were used as a second source of information. By doing so, individual differences between less and more tired patients could be revealed. The more a patient suffered from severe fatigue the higher his score on this question, while patients suffering from less severe fatigue scored lower or even zero on this question. Briefly, all patients felt able to exercise '*some kind of control*' over their fatigue, but patients that are more tired seemed to experience a lack of control due to RA fatigue more frequently.

Only two patients stated that the controllability depended on the inflammatory activity of their disease.

"Yes, one has influence on it. Mm. Yes through the things that I have already mentioned. But sometimes you can't control it. If flare-ups are coming and you really don't feel good. Then one also has a bad mood and then this tiredness comes up. In this respect, you do not always have control - flare-ups one cannot control – sometimes they are just there." (Patient 4)

Most of them used a mixture of personal and treatment control. Personal control was commonly demonstrated by repressing fatigue or resting/sleeping. Medication and treatments such as sleeping bags or relaxation techniques were reported as possible treatment controls. Although all patients believed in the persistence of RA fatigue, some patients believed in the possibility of recovery from RA fatigue. This possibility of recovery was seen in a cure for RA or a change of life style leading to decrease in medication – which mirrored their causal beliefs. The other patients did not believe in curability but they could imagine a variety of possible treatments to improve their fatigue. Due to the multi-complexity of RA fatigue one patient found it difficult to imagine a possible treatment.

An overview of the major differences and similarities between more and less tired patients regarding their illness perceptions of RA fatigue are shown in table 4.

Table 4. *Overview of major differences and similarities in illness representation between the two patient groups*

More tired patients	**Less tired patients**
Identity	Identity
Great variety and amount of physical and emotional symptoms	Great variety and amount of physical symptoms, but few/zero emotional symptoms
Differentiating between types of fatigue	Not differentiating between types of fatigue
Causes	Causes
Mostly chronic causes	Mostly episodic causes
Multiple causes, exacerbators and positive conditions	Multiple causes, exacerbators and positive conditions
Consequences	Consequences

Severe physical consequences	Less severe physical consequences
Severe cognitive consequences	Less severe cognitive consequences
Severe consequences for daily and social living	Less severe consequences for daily living and less severe/zero for social living
Severe emotional consequences	Less severe/zero emotional consequences
Positive consequences	Positive consequences
Timeline	Timeline
Persistence	Persistence
Mostly chronic	Mostly episodic
Unpredictability	Unpredictability
Control/Cure	Control/Cure
Controllable (self-efficacy)	Controllable (self-efficacy)
Outcome: frequently experiencing a lack of control due to RA fatigue	Outcome: less frequently experiencing a lack of control due to RA fatigue
Mix of personal and treatment control	Mix of personal and treatment control
Curability (some)	Curability (some)
Treatability	Treatability

2. *How do RA patients cope with their fatigue?*

In general, all patients seemed to have a broad repertoire of emotion- and problem-focused coping strategies (for an overview see table 5). Interestingly, no patient made use of avoidant/escape coping such as ‘*wishful thinking*’. In the following, the individual differences between more and less tired patients in coping behavior will be described.

Table 5. *Overview of applied problem-focused and emotion-focused strategies.*

Problem-focused coping strategies	**Emotion-focused coping strategies**
Taking control	*Exercising self-control*
— Repress/Ignore fatigue	— Upward/Downward comparison
— Taking stimulants	— Distancing
— Physical activity	— Self-disciplining
— Taking breaks	— Distraction
— Seeking instrumental support	— Communicate fatigue/ express feelings
— Resting/Napping/Relaxing	— Seeking support/understanding
Seeking information	*Positive reappraisal*
Proactive control	*Re-establishing positive affect*

- Organizing your day
- Staying fit
- Taking care of one’s limits
- Learning new skills
- Taking care of sleeping hygiene

More tired patients

More tired patients seemed to perceive RA fatigue as a psychological and physical burden one must take charge of. This mirrored their beliefs about ‘*identity*’ and ‘*consequences*’. They tended to ignore the symptoms of increased tiredness and appraised repressing fatigue as an effective coping strategy. The reported reasons for the effectiveness of this strategy were non-health related. For example, they appraised it as effective because they felt able to accomplish what they wanted to accomplish despite suffering from tiredness.

“Yes, I do not simply have that experience for a long time. I just know, that I feel tired. And I don’t want it then and influence myself with positive thoughts in order to wriggle out of it. Or like already said, simply begin to conduct a work, which you have to do at that moment. If you have finished everything in the evening, then that’s positive, so you can sit on the couch and say “now I’m tired”. (Patient 5)

Also, wishing to fulfil one’s professional or social roles was a commonly reported reason. In line with this, patients often used upward comparisons or self-disciplining thoughts to motivate themselves to keep on going.

“Sometimes you have such a day, then you are simply not able to, then you might think in the morning: Oh just stay at home. [...] Then you think, your work colleagues can indeed have the same. Are tired or something. Not only because I now have the disease. That’s why, then you simply pull yourself together and go to work.” (Patient 11)

Sometimes they ignored the symptoms of their body until having pushed it to limit. Their efforts to repress fatigue (as long as possible) also included efforts to delay the application of strategies such as resting and taking breaks. They mostly applied those strategies when already being confronted with symptoms of severe tiredness. Thus, they were not able to apply appropriate coping strategies in time and respond to the demands of the situation.

"Because, when I realize I'm getting tired, then I try to push through for 10 more minutes.. And if it really doesn't work out any longer, then I of course lie down. But, yes, I try to actually delay it a bit." (Patient 15)

Also, they appraised repressionof negative feelings associated with RA fatigue as effective. In their view, repressing or distancing oneself from negative feelings and thoughts about fatigue could prevent possible negative emotional consequences of fatigue on their lives.

"I don't really think about it. Because if I would think about it too much, it would become psychologically distressing again and I do not want it to. I repress it - I've built this wall, I don't let it get to me." (Patient 15)

In light of the greater perceived severity and impact of RA fatigue their coping with RA fatigue was assumed maladaptive. Despite being able to choose among a broad repertoire, consisting of problem-, emotion-focused and even proactive coping strategies, their application of coping strategies was rigid, delayed, and inflexible. In addition, by ignoring the symptoms of their body they were not able to respond to the demands of the situation at hand and thereby risked excessive demand on their resources.

The maladaptability of their coping efforts seemed to be due to their general preference to repress fatigue and negative feelings. Interestingly, they appraised their coping behavior as effective despite the fact that they experienced negative health outcomes. This discrepancy between appraised effectiveness of their coping efforts and the negative health-outcomes mirrored their answers concerning self-efficacy beliefs. During the interview, they reported to feel able to control their fatigue but their answers on the questionnaire indicated that they actually experienced a lack of control due to fatigue. Thus, it seemed that their beliefs about what they were capable to achieve did not match their objective capabilities.

Less tired patients

With respect to their cognitive representation of RA fatigue, this group of patients did not perceive RA fatigue and its associated symptoms as something negative which one must take charge of. Rather, they positively reappraised their fatigue as a useful warning signal for risking excessive demand on their resources. By drawing on their symptom perception as a useful source of information, they were able to exercise proactive control and prevent possible negative impacts such as a lack of energy the following day. Among their broad repertoire of proactive coping were actions or concepts like taking care of sleeping hygiene, organizing your day, staying fit, taking care of your limits and learning new skills such as meditation.

"You learn to listen to your body. I know just where my limits are and if one exceeds those limits it will affect your symptoms negatively. So as I have just said with my rhythm. If I ever get thrown out of it a bit, of course it can be adapted again, but I realize it because I am deprived of my activity then." (Patient 16)

Another advantage of being able to read the symptoms of their bodies was that these patients could time the use of coping strategies so those were congruent with the demands of the situation at hand. For example, they used a combination of stimulants, repression, and distraction in phases of low fatigue, stress, and illness activity, and a combination of resting/sleeping and taking breaks in times of intense fatigue, stress, and illness activity. This context-dependent use of coping strategies required flexibility and the ability to organize oneself.

"And [the rheumatic activity] did this have different effects on your life and the strategies you used?"

> *"The strategies are the same. Well, it does affect my life. Because then I have to plan ahead very differently." (Patient 13)*

Their context-dependent use of coping strategies mirrored their beliefs about causes and cure/control beliefs. The less tired patients held strong self-efficacy beliefs and some of them had a more differentiated perception of controllability.

"Do you think that you have a certain control over your fatigue?"

> *"Yes, to some extent. By sleeping enough and taking caffeine when I need it and by taking the time to take a break. By doing so, I can react and respond to it. So the fatigue itself, I cannot control but I can do what I can do, and that's what I do." (Patient 13)*

Contrary to the more tired patients, less tired patients tended to appraise making upward comparisons, ignoring or repressing fatigue and associated negative feelings when actually feeling tired or sad as ineffective.

"Well in the past, I didn't really accept it and I thought for quite a while, I have to fight this, and [...] I must achieve what others can achieve. And over time, I learned that you have your own workload and I

have actually learned to accept it and to take my time for it. If it does not work out, and of course to more look after what I can do to feel better. So for me personally then. So now I try to find my way for it." (Patient 13)

When it comes to dealing with negative feelings concerning fatigue, most of these patients regarded positive reappraisal, emotional support, or re-establishing positive affect as effective coping strategies.

"So if you don't perceive the things as negative - or regard them as positive or neutral, then you can cope with it more easily because they don't restrict you as much as they would otherwise. And if you - when fatigue occurs – tell yourself 'sweet, now I finally have a reason to lie down" then it is of course much better for your emotional functioning than if you tell yourself "Fuck, now I'm tired again and have to lay down again." (Patient 13)

"I have a social environment that completely supported me and if I didn't have had it – yes, they always have accepted that I behave as I feel and they never accused me for doing so. […] I really think that it is due to my social environment that I feel better now." (Patient 7)

Overall, these patients managed successful adaption to RA fatigue. Their coping their coping with RA fatigue and associated feelings was assumed adaptive because they were less tired than the more tired patients, and experienced less or even zero impact of RA fatigue on their life. By using the symptoms of their body as a source of information, they were able to flexibly apply coping strategies and thereby prevent negative health-outcomes. In addition, they effectively and in time matched their coping behavior with the demands of the situation at hand. They reported to have experienced negative emotional consequences in the past, having undergone a process of adaption. During this process, they had learned to accept RA fatigue as a part of their life and had adjusted their expectations of how much exertion they can afford. In contrast to the more tired patients, the less tired patients thereby managed to align personal believes about capabilities with their objective capabilities.

Special cases: tired despite adaptive coping

Two patients of the more tired group represented special cases. Although their coping behavior were more in line with those of the less tired group (adaptive coping behavior), they belonged to the more tired group concerning illness perceptions and greater felt severity/impact of fatigue.

They were conscious about the costs of ignoring the symptoms of their bodies for too long. In cases when they did, they experienced negative consequences such as great pain the following day.

"Yes, one simply knows it. Right now it's not that serious. But otherwise, it was always the case when I did too much one day and didn't take the time, then I didn't even have to try to plan something for the following day, because then I would achieve nothing [...] The body took back what you took from it the day before, where you have really exhausted yourself and did a lot. And the other day, that's always been so, then the body gets the rest back he really needed." (Patient 4)

Both patients had in common that they had already developed some forms of pro-active control like taking care of one's sleeping hygiene or organizing one's daily routine to prevent overburden. However, despite their ability to read the symptoms of their body and take preventive action, they experienced severe emotional distress because they knew that their desired capabilities did not match their objective capabilities. For example, their desired capabilities to fulfill their professional and social roles, which they did not have. This mirrored their perception of severe emotional and social consequences.

"Or if I am with my grandson, who is now three years old. This is insanely stressful for me, then. Because suddenly. I'm so tired. Then I can't go any longer. Yes, well and that makes me sad, that's what I feel as well so I feel it." (Patient 10)

More in line with the more tired patients coping behavior, they tended to make upward comparisons. Doing so resulted in an inner conflict between wishing to fulfill one's social role and at the same time knowing that one is at risk of exceed demand. This let them experience feelings of insufficiency and decreased self-esteem.

"Because you indeed want to be more efficient. Sometimes you just feel that everybody masters their life, except you. This self-esteem, it sometimes is way off. Now you need to rest again. Some people would work four hours instead – "and you don't even make it for two hours." (Patient 4)

Despite better knowledge, these patients sometimes exceeded their resources when trying to comply with the higher demands of their environment. This could result in a feeling of overburden and the strong need to seal oneself off.

"And then I also have my children, everyone always has their own concerns, with which they often approach me. And then, sometimes it's just all too much. And then uh, then I have the feeling of – please can't you just leave me alone. Then I just want to, yes, if I could just sit down somewhere, just resting your legs for a moment, not seeing or hearing anymore. Because sometimes, it just gets over my head. […] And I would just like to run away from it. Well, this feeling you sometimes have." (Patient 4)

They handled their negative emotions by acknowledging them, and tried to re-establish positive affect by listening to their favorite music or reminding themselves of their hope for a better tomorrow. This was more in line with the less tired patients.

"Yes, and when I get those feelings, it really is this way – I know it comes and it goes and I am practicing myself in patience. Then I think, it will get better. Tomorrow is a new day." (Patient 10)

Concluding, these two patients seemed to be trying to successfully adapt to RA fatigue but sometimes fell back into old patterns of coping. In addition, their awareness of the discrepancy between desired and objective capabilities let them experience severe emotional distress.

3. *How do the patients perceive the relationship between felt severity/impact of RA fatigue, their illness perceptions, and coping efforts?*

When asked about a possible relationship between felt severity/impact of RA fatigue, their illness perceptions and coping efforts all of the patients pointed to the importance of acceptance and a positive outlook on life when it comes to dealing with RA in general or symptoms such as fatigue.

"I think one really has to accept it and try to think positive by telling yourself 'Yes when you have this illness, it not worse if you sit down sometimes'. Some people believe that they have to keep on going at these moments but – hm – I do not see it that way. In my point of view, one has to accept one's illness – despite the fact that others don't see it that way" (Patient 4)

The patients who managed successful adaption to RA fatigue all reported to perceive such a connection. They stated that '*thinking positive*' is a mental attitude which makes it easier to flexibly cope with fatigue – in a sense of perceiving it as controllable and re-framing it as something neutral or positive.

"So if you don't perceive the things as negative - or regard them as positive or neutral, then you can cope with it more easily because they don't restrict you as much as they would otherwise. And if you - when fatigue occurs – tell yourself 'sweet, now I finally have a reason to lie down" then it is of course much better for your emotional functioning than if you tell yourself "Fuck, now I'm tired again and have to lay down again." (Patient 13)

Misleadingly, the more tired patients also pointed to the importance of '*positive thinking*'. However, their interpretation of '*positive thinking*' included focusing on the positive aspects of their life in order to restore energy/strength and keep on taking charge of fatigue.

"Because, when I realize I'm getting tired, then I try to push through for 10 more minutes. [...] Sometimes I succeed, sometimes I do not. It depends. But, I think if I had not had this positive attitude I could not control it – in a sense that – then I would have to lay down immediately and not in 10 minutes. It is a question of attitude, right?" (Patient 15)

Two patients found it hard to imagine a connection between thinking about fatigue and felt impact/severity of fatigue. They explained that they did not think about their fatigue, but had different reasons not to do so.

"I don't even think about it, it [fatigue] is simply there. It simply is a part of me, as if you're wearing a jacket [...] but YOU can take your jacket off, I can't take it off - but for me, it's inherent." (Patient 1)

"I don't really think about it. Because if I would think about it too much, it would become psychologically distressing again and I do not want it to. I repress it - I've built this wall, I don't let it get to me." (Patient 15)

DISCUSSION

The aim of this study was to increase our understanding of differences between more and less tired RA patients by investigating the relationship between illness perceptions about, coping with, and the perceived severity/impact of RA fatigue. This aim has been achieved. In the following, the results will be discussed in more detail.

Which illness perceptions do RA patients hold about fatigue?

With respect to the first research question, it can be stated that a great variance existed in the perception of fatigue among RA patients and that more and less tired patients differed in their illness perceptions about fatigue. In addition, individual differences in beliefs about '*consequences*' were congruent with individual differences in total and sub-scores of the BRAF-MDQ. On the one hand, this adds to the concurrent validity of the BRAF MDQ. On the other hand, it shows that reporting more and severe consequences might serve as indicator of greater perceived impact/severity of fatigue in RA.

Firstly, more tired patients perceived more and severe (especially emotional and social) consequences, while less tired patients perceived less and less severe consequences. This finding is in line with those of previous quantitative studies (Scharloo et al, 1999; Treharne et al., 2008), which also found greater perceived severity/impact of RA fatigue to be associated with the perception of severe consequences.

Secondly, more tired patients tended to perceive RA fatigue as a special kind of tiredness and associated it with a great variety of emotional and physical symptoms, while less tired patients did not distinguish between types of fatigue. Rather, they assumed RA fatigue to be an intense form of normal tiredness and associated it with a great variety of physical but few or even zero emotional symptoms. This finding is consistent with a quantitative study on the chronic fatigue syndrome conducted by Moss-Morris, Petrie and Weinman (1996), wherein identity beliefs were measured with the IPQ, and operationalized as the number and frequency with which symptoms are endorsed as part of the illness. A strong illness identity belief was later on found to be positively associated with a belief in serious consequences, which matches the finding of this study. But the current study adds (1) that more tired patients tend to differentiate between different kinds of fatigue while less tired patients do not, (2) that identity beliefs about RA fatigue can possibly change over time and (3) that some patients perceive positive consequences, which is in line with the study of Nikolaus, Bode, Taal & van de Laar (2009).

Thirdly, Moss-Morris, Petrie & Weinman (1996) revealed that a more chronic timeline perception concerning the chronic fatigue syndrome was also positively related to the perception of severe consequences. The current study is mostly in line with this finding. Most of the more tired patients tended to assume their RA fatigue to be chronic. In contrast, the majority of the less tired patients tended to belief their fatigue to be episodic. Patients who perceived RA fatigue as occurring ad hoc, assumed RA fatigue to be a special kind of fatigue, due to this ad hoc occurrence. The belief in an ad hoc occurrence was found in combination with chronic as well as episodic timeline beliefs and among more as well as less tired patients, which shows that perceiving severe consequences seems to be a better indicator for RA patients suffering from severe fatigue than beliefs about the label or timeline of RA fatigue.

Fourthly, when it comes to causal beliefs, patients with chronic timeline beliefs tended to report causes that were more chronic, for example ageing or a chronic RA. Patients who perceived it to be episodic reported episodic causes like acute episodes of their RA. Concerning exacerbators, most patients – regardless of the other illness perceptions they held – perceived having a job and general stress to play a role in increasing fatigue. Furthermore, autonomy at work and perceived social support emerged as buffering factors against possible negative impacts of RA fatigue. In general, all patients reported multiple causes and exacerbators, which is in line with the current state of research viewing RA fatigue as multi-causal (Hewlett, Nicklin & Treharne, 2008; Pollard et al., 2006; Treharne et al., 2008; Hewlett et al., 2011).

Fifth, with respect to control/cure beliefs about fatigue the current study revealed a discrepancy between answers during the interview and scores on the questionnaire for patients that are more tired. During the interview, more tired as well as less tired patients stated that they felt able to exercise some control over their fatigue – indicating strong self-efficacy beliefs. This matches the findings of a quantitative cross-sectional study by Huyser et al. (1998), which found self-efficacy beliefs not to be associated with differences in perceived severity/impact of RA fatigue. However, when the patients' answers on the questionnaire were used as a second source of information, more tired patients seemed to experience a lack of control due to RA fatigue more frequently than less tired patients. One the one hand, more tired patients might be assumed to hold less strong self-efficacy beliefs about RA fatigue. This would be consistent with previous longitudinal as well as cross-sectional quantitative studies, which found a lower self-efficacy belief to be a predictor of or to be associated with greater fatigue (Treharne et al., 2008; Brekke, Hjortdahl, and Kvien, 2001, 2003). On the other hand, more tired patients might be assumed to engage in '*self-inefficacious thinking*'. The latter hypothesis will be discussed in more detail in the following section on coping with RA fatigue.

How do RA patients cope with their fatigue?

Concerning the second research question, all patients seemed to have a broad repertoire of emotion- and problem-focused coping strategies. However, individual differences were found concerning the adaptability/maladaptability of their coping behavior and the appraisal of the effectiveness of particular coping strategies. Based on differences in health-outcomes (severity/impact of RA fatigue) the coping behavior of less tired patients were assumed adaptive and those of more tired patients maladaptive.

Firstly, none of the patients used '*wishful thinking'* in order to cope with RA fatigue. This finding contrasts with those of previous quantitative studies (Hoogemoed et al., 2010; Scharloo et al., 1999). Those studies found greater perceived severity/impact of RA fatigue to be mediated by the coping strategy '*wishful thinking'*. More consistent with the finding of the current study, Treharne et al. (2008) found '*wishful thinking* not to be a mediator. However, unlike previous studies, the current study examined which coping strategies were used as well as the adaptability/maladaptability of their coping behavior. Examining the adaptability/maladaptability of coping behavior seemed to reveal individual differences, while examination of the repertoire of coping strategies did not. Hence, the findings on '*wishful' thinking*' in previous studies might be due to solely focusing on the repertoire of coping strategies – which reveals nothing about the adaptability/maladaptability of a strategy.

Secondly, less tired RA patients' coping behavior was characterized by a greater flexibility and better timing. More tired RA patients were rigid and worse in timing their application of coping strategies. Thereby they failed to take full advantage of their broad repertoire of coping strategies.

Thirdly, less tired patients made use of the feedback of their bodies and regarded fatigue to be a helpful warning signal, which makes it possible to proactively cope and prevent excessive demand on resources as well as associated negative consequences. In contrast, more tired patients regarded fatigue as something burdening one has to cope with by ignoring the symptoms of one's body and repressing symptoms of tiredness and associated negative feelings. By doing so, they risked excessive demand and associated severe consequences.

Fourthly, less tired patients appraised repression or taking stimulants as effective in situations of low fatigue or stress, where they did not lead to negative health outcomes such as intense stress or fatigue. Thus, their appraisal of the effectiveness of a strategy depended on the context and expected effect on health outcomes. More tired patients had a general preference for the coping strategy repression. Their appraisal seemed to be dependent on the effectiveness of this strategy in achieving non-health related goals even if those goals were health damaging.

Learly et al. (1994) referred to this phenomena as '*self-presentation*'. Self-representation describes a pursuit of non-health related goals that might be health damaging. Self-presentation was assumed to occur when people try to avoid negative non-health related outcomes such as disturbed interpersonal relationships, even on the cost of possible negative health outcomes. Thus, the maladaptive coping behavior of more tired patients might stem from a different hierarchy of goals, wherein health-related goals are less important than non-health related goals.

Fifthly, less tired patients managed to align personal beliefs about their capabilities to control their fatigue with their objective capabilities, while more tired patients did not. Rimal (2000) defined this discrepancy between perceived and objective capabilities as '*self-inefficacious thinking*' and explained why, despite knowing what to do and having the required skills to do so, some people failed to manage situations effectively. A discrepancy between strong self-efficacy beliefs and limited success in controlling their fatigue might explain why most more tired patients fail to cope with their fatigue effectively, despite knowing that they are tired and having the required repertoire of coping strategies to do so.

Sixthly, less tired patients seemed to cope more easily with RA fatigue – in the sense that they did not experience severe emotional distress. Though they stated to have experienced negative emotional consequences in the past, they had undergone a process of adaption. During this process, they adjusted their expectations of what they can achieve and thereby they managed successful adaption to RA fatigue. This phenomenon was also described in previous studies on coping with chronic illness (Brownless et al., 2000; Heinrich et al., 1994). These studies found that people who face a chronic illness such as RA manage to maintain the phenomenology of a stable and positive self by reformulating their future self-conceptions to be compatible with the limitations of illness. Thus, the successful adaption to RA fatigue of less tired patients might be due to a reformulation of their self-concept. Furthermore, the findings on self-conceptualization might explain why some people engage in '*self-representation*', engage in '*self-inefficacious thinking*' or belong to the more tired patient group despite showing substantial sings of adaptive coping behavior (special cases). Perceiving a discrepancy between actual-self and future-self might lead to the perception of RA fatigue as something that hinders a person in being the person they want to be or in doing the things they want to do. Increased fatigue might serve as a reminder of the limits of one's own capabilities, the limits of attaining one's health and non-health related goals and, most important the limits of reachability of one's ideal self. Knowing or actually experiencing that this discrepancy exists might be associated with severe emotional distress. Perceiving RA fatigue as something negative/burdening, engaging in '*self-representation*' and/or '*self-inefficacious thinking*' as well as having/falling back into a maladaptive coping pattern (special cases) might therefore be viewed as an unwillingness to adjust one's ideal self.

Lastly, two more tired patients represented special cases. Although their coping behavior was more in line with those of the less tired group (adaptive coping behavior), they belonged to the more tired group concerning illness perceptions and greater felt severity/impact of fatigue. Concerning the two views in illness perception research, they might be suitable examples for the direct link between illness perceptions and health-outcome (Petrie & Pennebaker, 2008). This means that, holding a particular set of illness beliefs about RA fatigue might lead to negative health-outcomes (greater severity/impact of RA fatigue), whether in combination with maladaptive or adaptive coping behavior. Furthermore, less tired patients might illustrate the indirect link between illness perceptions and health outcomes via coping. In other words, RA patients with positive health-outcomes (less severity/impact of RA fatigue) mostly showed a combination of an adaptive coping behavior and a set of illness perceptions similar to that of the less tired group. Thus, when it comes to successful adaption to RA fatigue the dynamic interaction between coping behavior and illness perceptions seems to be important.

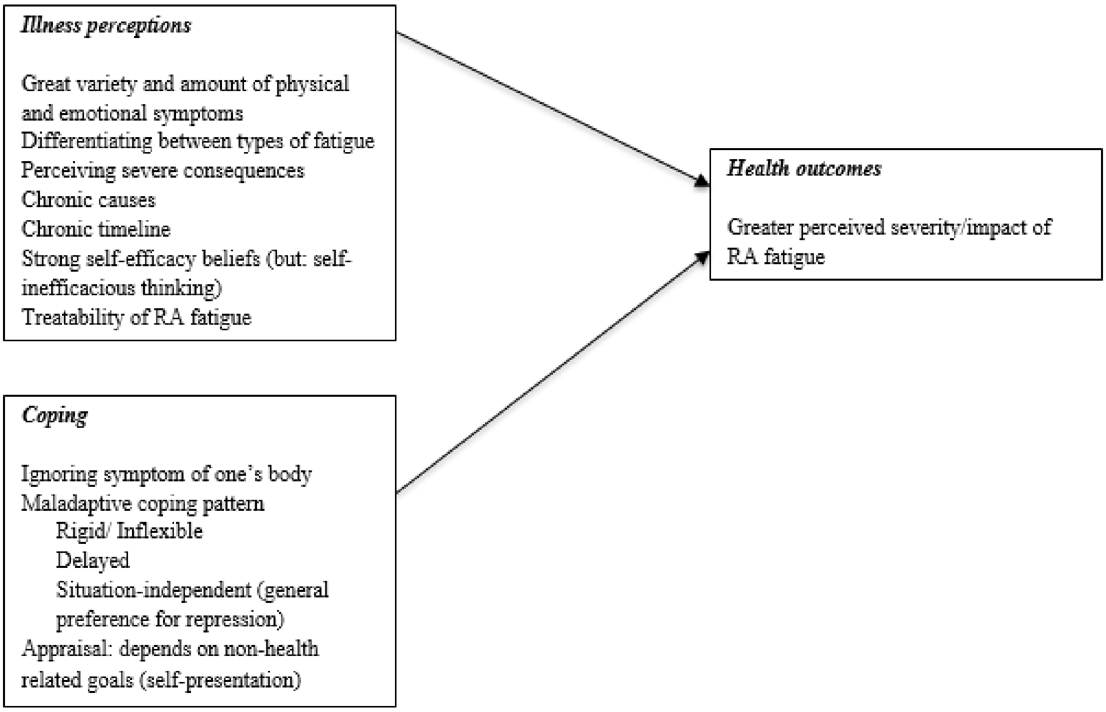
How do the patients themselves perceive the relationship between felt severity/impact of RA fatigue, their illness perceptions, and coping efforts?

In general, most of the patients perceived such a connection and stated more or less explicitly that acceptance is important. Additionally, answers on this question frequently included the term '*positive thinking*', but what was meant by this term varied greatly. While less tired patients interpreted '*positive thinking*' as a mental attitude which makes it easier to flexibly cope with fatigue, more tired patients viewed it as mental attitude which makes it easier to restore energy/strength and keep on taking charge of fatigue. Lastly, two patients found it hard to imagine a possible connection, which might due to the complexity of the question. During the interview they repeatedly stated that they found the question hard to understand.

Revisions of the heuristical model

Proceeding the study a heuristical model of the relationships between the three constructs was developed. For one out of the three hypothesis support was found. More tired RA patients perceived severe consequences of RA fatigue. Concerning control beliefs, the hypothesis of a discrepancy between strong self-efficacy beliefs and objective outcome of the control efforts seemed to be more correct ('*self-inefficacious thinking*'). Concerning '*wishful thinking',* no support was found. The revised heuristical model illustrating the findings on more tired patients is shown in figure 2.

Figure 2. *Revised heuristical model of the relationships between the three constructs*



Limitations

According to Cohen, Manion and Morrison (2011) qualitative research validity can be increased by minimizing the amount of bias as much as possible. One source of bias are characteristics of the interviewer. Therefore a possible limitation of the current study might lay in the use of a mixed deductive and inductive coding scheme which could include some of the pre-existing beliefs of the researcher in the beginning of the study. However, the researcher's efforts to stay conscious of possible biases are reflected in the results about control beliefs and the coping strategy '*wishful thinking*' which balances this possible limitation to a certain degree.

Another limitation of the study is that the interviews were coded by one researcher and therefore may lack intercoder reliability. During content analysis intercoder reliability gives an indication of the agreement between two researchers about the labels given to the data (Tinsley & Weiss, 1975, 2000). According to Neuendorf (2002) intercoder reliability is important, although it does not ensure validity. The reason for this is: when intercoder reliability can be doubted, the validity of the data and interpretations can be doubted, too (Neuendorf, 2002). However, two other researchers reviewed the study and found the findings supported by the selected citations which generalize this possible limitation to a certain degree.

In addition, a major limitation of the study is that the presumed differences between the more and less tired patients are far from clear-cut. For example, in both groups episodic as well as chronic timeline beliefs and substantial signs of adaptive coping behavior were found.

Therefore, the statistical significance of the presumed individual differences might be doubted. Rather than performing statistical analysis, qualitative studies look for trends in the data by comparing interviews for similarities and differences. Trends are statements that are heard by most of the people who took part in a study. During the data-analysis of the current study, it was searched for group-trends (more tired vs. less tired group) by comparing the interviews of each group for similarities and differences in illness perceptions and coping efforts. These group-trends are qualitative in nature and cannot be subject ed to quantitative analysis. For example, quantitative data can be validated by calculating a p-value or an effect size but trends not. Therefore, the presumed differences between more and less tired patients must be considered with caution and additional – especially quantitative research –is needed.

Moreover, the generalization of the results might be limited due to the asymmetrical gender distribution in the sample (men were underrepresented). Lastly, concerning the ambiguity of certain terms such as '*positive thinking*' or '*some kind of control*' this study is representative for the limitations of qualitative research in general. The strength and the weakness of qualitative research is the fact that it examines the truth that is in the eye of the beholder – in the sense that the data is based on participants' own categories of meaning (Cohen, Manion & Morrison, 2011). One the one hand, this makes it possible to describe phenomena situated and embedded in local contexts in rich detail and to discover complexities that are often missed out by quantitative research. On the other hand, it makes it difficult to generalize the findings to other populations or contexts.

Strengths, utility for future research and interventions

The major strength of this study is that it helps to unravel individual differences in felt severity/impact of RA and shows how these differences connect to individual differences in illness perception and coping behavior. In addition, it points to the importance of psychological factors when it comes to RA fatigue. Concerning future research the heuristical model (as shown in figure 2.) might serve as a source for hypothesis. For example, by use of a quantitative design it could be tested, if the presumed individual differences in illness perceptions and coping behavior between more and less tired patients are significant. Furthermore, the role of RA patients´ self-concepts seems to be a fruitful research topic when examining differences between more and less fatigued RA patients. The reason for this it that perceiving RA fatigue as something negative/burdening, engaging in '*self-representation*' and/or '*self-inefficacious thinking*' as well as having/falling back into a maladaptive pattern of coping (special cases) might be explained by an unwillingness to adjust one's ideal self.

Lastly, the findings of the current study might be informative for future interventions. Concerning the development of interventions for improving fatigue in RA patients, both RA patients´ illness perceptions and coping behavior should be taken into account. The reason for this is that, concerning the successful adaption to RA fatigue the findings suggest that it is the dynamic interplay between illness perceptions and coping behavior, which is important. Studies on the chronic fatigue syndrome could serve as prototypes for the development of such interventions. For instance, a study by Moss-Morris, Sharon, Tobin and Baldi (2005) showed that changing patients' illness perceptions about chronic fatigue syndrome by a graded exercise intervention could improve chronic tiredness. Furthermore, the findings of the current study suggest that patients who successfully managed to adapt to RA fatigue might serve as role models in self-management programs.

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APPENDIX I

Interview scheme

Interview question	Construct	Analysis / Results
Jeder kennt das Gefühl müde zu sein. Sei es am späten Abend oder nach dem Sport. Diese Art Müdigkeit hat einen vorübergehenden Charakter. Anders ist das bei vielen entzündlich-rheumatischen Erkrankungen, sowie rheumatoider Arthritis. Es gibt Hinweise darauf, dass die Müdigkeit bei dieser chronischen Krankheit einen anderen Charakter hat. Viele Betroffene können für ihre Müdigkeit keine Ursachen nennen und auch schlecht Voraussagen treffen über ihre Müdigkeitsbeschwerden. Auch machen sie die Erfahrung, dass ihre Müdigkeit sie ständig oder zumindest über weite Strecken begleitet und durch ausruhen kaum positiv zu beeinflussen ist.	*General introduction interview topic.*	
Um einen Eindruck der Intensivität ihrer Müdigkeit zu bekommen, möchte ich sie bitten vorab kurz diesen Fragebogen auszufüllen.	*Perceived fatigue severity/impact*	Quantitative, SPSS Categorical analysis (use of median as criteria to differentiate between more or less fatigued
Erstes möchte ich Ihnen allgemeine Fragen zu Ihrer Person stellen.	*Demographics*	

Geschlecht, nur notieren, nicht erfragen	Gender	Note → Categories (male/female)
Wie alt sind Sie?	Age	Note, Citations
Was ist Ihr Familienstand?	Relationship	Note, Citations
Was ist Ihr höchster Bildungsabschluss? — Hauptschule — Realschule — Fachabitur — Abitur — Hochschulabschluss — Anderen Schulabschluss — Schule beendet ohne Abschluss —	Educational level	Note, Citations → Categories
Was ist ihre gegenwärtige berufliche Situation? — Berufstätig — Frührente — Altersrente — Arbeitsunfähigkeitsrente — In Ausbildung — Hausfrau/Hausmann	Career	Note, Citations → Categories
Welchen Beruf üben Sie zurzeit aus oder haben Sie zuletzt ausgeübt? — Berufstätig — Momentan ohne Beruf	Job situation	Note, Citations → Categories
Wie lange leiden Sie bereits an Ihrer Krankheit, in Jahren?	*Information about RA* Disease duration	Note, Citations

Leiden Sie an weiteren Erkrankungen neben Ihrer rheumatoiden Arthritis?	Comorbidity	Note, Citations
Gehen Sie zu einem Rheumatologen? Nehmen Sie regelmäßig Medikamente ein? Nehmen Sie noch andere Behandlungen in Anspruch?	Treatment of RA (medicine, other treatments)	Note, Citations
Haben Sie Schlafschwierigkeiten?	Sleep difficulties	Note, Citations → Categories (Yes/No)
Vielen Dank. Als nächstes folgen Fragen über Ihre persönliche Einschätzung des Symptoms Müdigkeit. Gefragt sind in unserem Gespräch einzig Ihre persönlichen Erfahrungen, bei evtl. Symptomatik. Nur Sie persönlich können Ihren eigenen Lebensalltag mit dem Umstand „Müdigkeit“ bewerten. Daher gibt es infolgedessen keine Richtig oder Falsch sondern es geht allein um Ihre persönlichen Eindrücke und Gefühle. Scheuen sie sich nicht, mich bei Unklarheiten oder Fragen direkt anzusprechen. Ihre Unterstützung bietet uns die Möglichkeit einen wissenschaftlichen Beitrag für	*Introduction – structure of the interview on fatigue in RA*	

die Forschung zu leisten, damit effektive Behandlungsmöglichkeiten entwickelt werden können. Das Interview wird ungefähr 30-60 Minuten dauern. Zum Zweck einer späteren Verarbeitung der gesammelten Informationen wird das Interview aufgezeichnet. Alle Informationen werden dabei vertraulich behandelt und nicht an Dritte weitergegeben. Die Ergebnisse dieser Studie werden sich auf alle Teilnehmer beziehen. Zum Zwecke der Verdeutlichung können jedoch Zitate von Einzelpersonen verwendet werden. Informationen über alle Interviewteilnehmer werden hierbei anonymisiert. Das Ziel unserer Studie ist es Informationen zu sammeln über das Erleben von Müdigkeit bei RA. Hierbei werde ich auf folgende Aspekte Ihrer Müdikeitserfahrung eingehen: (1) Wie erfahren Sie Ihre Müdigkeit? (2) Wie denken Sie über Ihre Müdigkeit? (3) Wie gehen Sie mit Ihrer Müdigkeit um? Und (4) Wie tauschen Sie sich mit Anderen über Ihre Müdigkeit aus? Sollen wir beginnen?		

	Illness perceptions (1) Identity	
Wie würden Sie das Müdigkeitsgefühl beschreiben, welches Sie in Bezug auf Ihre Krankheit erfahren? ***Hilfe***: Wie würden Sie Ihre Erfahrung mit Müdigkeit Ihrem Partner/ Freund gegenüber beschreiben?	— Label (general definition)	Citation
Wie äußert sich diese Form von Müdigkeit? Woran merken Sie z.B. dass sie mal mehr oder mal weniger anwesend ist? Wie sind Ihre Gefühle in Bezug auf diese eben beschriebene Müdigkeit?	— Symptoms	
Könnten sie zu ihrer Müdigkeit bei RA einen Unterschied benennen, im Vergleich zu „normaler“ Müdigkeit z.B. Erschöpfung in Folge normaler Tagesaktivitäten. — Wie würden Sie diesen Unterschied beschreiben? — Kennen Sie noch andere Formen von Müdigkeit? — Wie erfahren Sie diese? — Was unterscheidet sie von einander?	— Identity (more precise definition)	
Vielen Dank. Nun möchte ich Sie gerne zu Ihrer persönlichen	New topic: (2) Causes	

Einschätzung über die Ursachen Ihrer Müdigkeit befragen. Hier geht es nicht um Medizinisches Fachwissen oder ähnliches. Mich interessiert wie Sie persönlich darüber denken.		
Menschen haben Ihre eigenen Vorstellungen davon, was ihre Müdigkeit verursacht. Wo liegen Ihrer Meinung nach die Ursachen für Ihre Müdigkeit im Rahmen ihrer Erkrankung?	(2) Causes	Citation
Vielen Dank. Im Folgenden möchte ich auf eventuelle Auswirkungen eingehen, welche Ihre Müdigkeit auf Ihr Leben hat.	New topic: (3) Consequences	
Wenn Sie Ihre Müdigkeit der letzten 7 Tage auf einer Skala von 1 bis 10 beschreiben sollten, wobei 1 bedeutet ‘’nicht müde’’ und 10 extrem müde: Wo würden Sie Ihre Müdigkeit einordnen?	(3) Consequences — Perceived severity of fatigue	Citation
Wie beeinflusst Ihre Müdigkeit Ihr tägliches Leben? — **Wenn nur auf negative Auswirkungen eingegangen wurde**: Könnten sie auch positive Einflüsse auf ihren Lebensalltag benennen?	— Fatigue’s likely impact on life (negative and positive)	

Wie wirkt sich Ihre Müdigkeit auf das Leben anderer aus?		
Vielen Dank. Als nächstes möchte ich Sie zu dem Verlauf Ihrer Müdigkeit befragen.	New topic: (4) Time line	
	(4) Time line	
Erinnern sie sich, wann ihnen diese Form der Müdigkeit zum ersten Mal bewusst wurde?	— First time	Citation
Würden Sie Ihre Müdigkeit als akut (einmal ganz schlimm, aber dann wieder weg wie eine Erkältung), episodisch (Zeiten wo sie wohl auftritt, wechseln sich mit Zeiten wo sie nicht auftritt ab) oder chronisch (immer anwesend, mal in stärkerer Mal in abgeschwächter Form) beschreiben? Oder würden sie einen anderen Begriff wählen? Blicken wir kurz auf ihre Zukunft: Wie denken Sie, wird es in 1 Jahr um Ihre Müdigkeit bestellt sein?	— Course	
— Wird sie sich verändert haben? — Denken sie: Wird sich diese Form der Müdigkeit ihr weiteres Leben begleiten?	— Duration (overlap with cure beliefs)	
Vielen Dank. Ich möchte nun darauf eingehen, welche Methoden oder Strategien Sie nutzen um mit Ihrer Müdigkeit	New topic: (5) Control/ cure (self-efficacy) → coping	

umzugehen und wie Sie selbst über Ihre Möglichkeiten dies bezüglich denken.		
	Coping	
Wie gehen Sie mit Ihrer Müdigkeit um? Haben sie konkrete Methoden, die Sie nutzen um mit Ihrer Müdigkeit zurecht zu kommen? Gibt es Strategien, die sich für Sie besonders wirkungsvoll erwiesen haben?	Coping strategies	Citation
— Was kann der Grund dafür gewesen sein?	— Perceived effectivity of those strategies	
Gibt es Strategien, die sich als besonders uneffektiv erwiesen haben? — Was kann der Grund dafür gewesen sein? Gibt es Strategien, die sich in einer Situation als wirkungsvoll herausgestellt haben, aber in anderen Situationen nicht? — Was glauben Sie, ist der Grund, dafür? Können Sie bestimmte Strategie effektiver/weniger effektiv anwenden, wenn Sie in einer bestimmten Stimmung sind? — Was denken Sie, warum sind die Strategien in den bestimmten Stimmungen mehr oder wenig effektiv?		
Denken sie, dass sie ihre Müdigkeit beeinflussen können?	Self-efficacy beliefs or (6) control beliefs	Citation

Wie gehen Sie mit Gefühlen um, die mit Ihrer Müdigkeit einhergehen? Glauben Sie, dass es jemals eine Behandlungsmethoden für (oder ein Medikament gegen) Ihre Müdigkeit geben wird? Wenn ja, was denken Sie, kann getan werden?	Coping with emotions related to RA fatigue (6) Cure beliefs	Citation Citation
Wir sind nun ausführlich darauf eingegangen, was Müdigkeit für Sie bedeutet, wie Sie darüber denken und wie Sie damit umgehen. Als nächstes möchte ich Ihnen eine Frage zu einem möglichen Zusammenhang davon stellen, denn...’	*New topic*	
...In der Forschung gibt es die Idee dass die Müdigkeit damit zusammenhängt, wie man darüber denkt und wie man damit umgeht. Wie sehen Sie das? — Wenn ja, wie sieht dieser Zusammenhang Ihrer Meinung nach aus? — Wenn nein, warum nicht?	*Relationship between the illness perceptions and coping and perceived severity/ impact of fatigue*	Citation
Vielen Dank. Abschließend möchte ich Sie fragen: — Haben Sie noch Fragen oder weitere Anmerkungen?	*Additional questions*	Citation
Wir sind am Ende unseres Interviews angekommen. Ich möchte mich herzlich bei Ihnen	*End of the interview*	

für Ihre Offenheit und Zeit bedanken. Falls Sie später noch Fragen oder Anmerkungen haben sollten können Sie sich jeder Zeit an mich oder meine Kollegin wenden. Unsere Kontaktdaten haben Sie ja noch? Über allgemeine Ergebnisse werde ich sie, auf Wunsch, nach Ablauf der Studie informieren. Einen schönen Tag noch.		

APPENDIX II

Informed Consent (German) Inga Thieler und Anna Dermer, 2015

Informed Consent

EINWILLIGUNGSERKLÄRUNG FÜR DIE TEILNAHME AN DER WISSENSCHAFTLICHEN STUDIE: MÜDIGKEIT BEI RHEUMATISCHER ARTHRITIS

Allgemeine Informationen zu dieser Studie

Diese Studie findet im Rahmen einer Bachelorarbeit im Fach Psychologie statt und wird von den Dozenten Dr. C. Bode und Dr. E. Taal der Universität Twente begleitet. Jeder kennt das Gefühl müde zu sein. Sei es am späten Abend oder nach dem Sport. Diese Art Müdigkeit hat einen vorübergehenden Charakter. Anders ist das bei vielen entzündlich-rheumatischen Erkrankungen, sowie rheumatoider Arthritis. Es gibt Hinweise darauf, dass die Müdigkeit bei dieser chronischen Krankheit einen anderen Charakter hat. Viele Betroffene können keine Ursachen nennen für ihre Müdigkeit und können schlecht Voraussagen treffen über ihre Müdigkeitsbeschwerden. Auch machen sie die Erfahrung, dass ihre Müdigkeit sie ständig oder zumindest über weite Strecken begleitet und durch ausruhen kaum positiv zu beeinflussen ist. Auf diese Form von Müdigkeit möchte ich in unserem Gespräch eingehen.

Zielsetzung der Studie

Der Zweck dieser Studie besteht darin, Informationen über die Erfahrung von Müdigkeit bei rheumatischer Arthritis zu sammeln. Hierbei werde ich auf folgende Aspekte Ihrer Müdikeitserfahrung eingehen: (1) Wie erfahren Sie Ihre Müdigkeit? (2) Wie denken Sie über Ihre Müdigkeit? (3) Wie gehen Sie mit Ihrer Müdigkeit um? Und (4) Wie tauschen Sie sich mit Anderen über Ihre Müdigkeit aus? Um auf das oben beschriebene Müdigkeitsgefühl bei rheumatoider Arthritis näher eingehen zu können, möchte ich im Folgenden mit Ihnen ein Interview führen. In diesem Interview werde ich Ihnen Fragen zu den oben genannten vier Aspekten und einige allgemeine Fragen stellen. Abschließend haben Sie noch die Möglichkeit Anmerkungen zu äußern und Fragen zu stellen. Ich möchte noch einmal deutlich darauf hinweisen, dass es keine richtigen und falschen Antworten gibt, sondern Ihre persönlichen Gedanken, Gefühle und Erfahrungen zentral stehen.

Was kommt auf Sie zu?

Das Interview wird ungefähr 30-60 Minuten dauern. Zum Zweck einer späteren Verarbeitung der gesammelten Informationen wird das Interview aufgezeichnet. Alle Informationen werden dabei vertraulich behandelt und nicht an Dritte weitergegeben. Die Ergebnisse dieser Studie werden sich auf alle Teilnehmer beziehen. Zum Zwecke der Verdeutlichung können jedoch Zitate von Einzelpersonen verwendet werden. Informationen über alle Interviewteilnehmer werden hierbei anonymisiert.

Einwilligungserklärung

Ich wurde vollständig informiert über das Forschungsvorhaben. Ich habe die schriftlichen Informationen über die Studie vollständig gelesen und verstanden. Mir wurde die Gelegenheit eröffnet um Fragen über die Studie zu stellen und meine Fragen wurden zur meiner Zufriedenheit beantwortet. Ich hatte genügend Zeit und Informationen um über die Teilnahme an dieser Studie nachzudenken. Ich kann meine Zustimmung jeder Zeit zurückzuziehen ohne Angaben von Gründen. Ich kann jederzeit Fragen über die Studie oder das Interview stellen.

Ich stimme zu, dass das Interview aufgezeichnet werden darf und anonymisierte Zitate für Forschungszwecke verwendet werden dürfen.

Ich stimme der Teilnahme an dieser Studie zu.

Name und Unterschrift Interviewteilnehmer
TT-MM-JJJJ, Gronau

Name und Unterschrift Untersucher
TT-MM-JJJJ, Gronau

APPENDIX III

Flyer

MÜDIGKEIT BEI RHEUMA

BACHELORARBEIT IM FACH PSYCHOLOGIE

WAS IST MÜDIGKEIT?

Jeder kennt das Gefühl müde zu sein. Sei es am späten Abend oder nach dem Sport. Diese Art Müdigkeit hat einen vorübergehenden Charakter. Anders ist das bei vielen entzündlich-rheumatischen Erkrankungen, sowie rheumatoider Arthritis. Es gibt Hinweise darauf, dass die Müdigkeit bei dieser chronischen Krankheit einen anderen Charakter hat. Viele Betroffene können keine Ursachen nennen für ihre Müdigkeit und können schlecht Voraussagen treffen über ihre Müdigkeitsbeschwerden. Auch machen sie die Erfahrung, dass ihre Müdigkeit sie ständig oder zumindest über weite Strecken begleitet und durch ausruhen kaum positiv zu beeinflussen ist.

Obgleich eine viel vorkommende Beschwerde, ist das Phänomen Müdigkeit bei rheumatischer Arthritis noch nicht ausreichend erforscht, was mit ein Grund für das Fehlen von effektiven Behandlungsmöglichkeiten ist.

Daher ist das Ziel unserer Studie, einen kleinen wissenschaftlichen Beitrag zu leisten, um die Forschung auf diesem Gebiet voran zu treiben. Dabei wollen wir den folgenden Fragen auf den Grund gehen:

Was verstehen Menschen mit rheumatoider Arthritis unter Müdigkeit? Was bedeutet sie für Betroffene? Wie gehen Sie damit um? Und welche Unterstützung erfahren Sie beim Umgang mit Müdigkeit?

INTERESSE GEWECKT?

Dann würden wir uns freuen, wenn wir ein persönliches Gespräch mit Ihnen führen dürfen (30-60 min).

Dieses Gespräch kann in den Räumen der Rheumaliga Gronau oder privat stattfinden. Termine sind auf Absprache vereinbar.

NEHMEN SIE KONTAKT MIT UNS AUF

Sie erreichen uns unter den folgenden Angaben:

Inga Thieler
Tel. X

Anna Dermer
Tel. X

UNIVERSITY OF TWENTE.

APPENDIX IV

General taxonomy

1. **General information**
    - Age
    - Gender
    - Work situation
    - Career
    - Relationship
    - Housing situation
    - Educational level
2. **Rheumatoid Arthritis & fatigue**
    - Disease duration
    - Medication
    - Comorbidity
    - Fatigue severity (BRAF)
    - Sleep difficulties
3. **Perception of fatigue**
    - ***Identity***
        - Label
            - No difference/Normal increased tiredness
            - Difference
                - Leaden tiredness
                - Disheartened tiredness
        - Symptoms
            - Physical
            - Emotional
    - ***Causes***
        - Causes
            - RA/weakened immune system
            - Medicine/Nutrition
            - Aging
            - Sleep hygiene
            - Comorbidity
        - Exacerbators

    - Lack of social support
    - Physical activity (inactivity)
    - Physical activity (more such as daily tasks)
    - Having a job
    - Mood
    - Weather
    - Worries/Fears
    - Bad physical condition

- ***Consequences (impact of RA fatigue)***
  - Physical
  - Living/Social
  - Cognitive
  - Emotional
  - Positive
- ***Time line***
  - Chronic/Cyclical/Acute
  - Future
  - Predictability
- ***Controllability/ Curability (self-efficacy)***
  - Self-confirmation
  - Symptom control
  - Treatment control
  - Recovery

4. **<u>Coping</u>**

- ***Problem-focused coping strategies***
  - Taking control
  - Seeking information
  - Proactive control
- ***Emotion-focused coping strategies***
  - Exercising self-control
  - Positive reappraisal
  - Exercising self-control
  - Reestablish positive affect
- ***Adaptability/Maladaptability***
  - Timing
  - Flexibility/Regidity

        - Context-dependence
    - ***Appraisal of effectiveness of coping strategy***

5. ***Connection***

- Yes
- No
- Partly