How are Competence, Autonomy and Relatedness associated with Fatigue in Rheumatoid Arthritis?

-A Qualitative Study-

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Content

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Samenvatting

Introductie: Naast de gebruikelijke symptomen van reumatoïde Artritis (RA) rapporteren patiënten verder dat ze extreem vermoeid zijn. Deze vorm van vermoeidheid verschilt van gewone vermoeidheid omdat ze abrupt optreedt. Om beter in het dagelijkse leven te kunnen functioneren, passen RA patiënten coping strategieën toe zoals prioriteiten opstellen of plannen maken. Volgens de zelfdeterminatie theorie kan psychologisch welbevinden plaats vinden als de basis behoeften competentie, autonomie en verbondenheid vervuld zijn wat vervolgens ook de basis voor optimaal functioneren is.

Methode: De studie bestudeert de drie basis behoeften als beweegredenen om met vermoeidheid om te gaan. In semigestructureerde interviews werden 13 RA patiënten met vermoeidheid (gemiddelde leeftijd = 47,62 jaar) individueel geïnterviewd. Verder werden de patiënten opgedeeld in twee leeftijdsgroepen, namelijk jongere (spreiding = 22-34) en oudere (spreiding = 50-79) patiënten. De analyse werd met behulp van zowel een top-down en een bottum-up coderingsschema uitgevoerd.

Resultaten: Met betrekking tot de drie basisbehoeften werden zowel ondersteunende als dreigende aspecten voor het dagelijkse omgaan met vermoeidheid gevonden. Ten aanzien van competentie werden het begrip waar vermoeidheid vandaan komt en het vertrouwen in de toekomst als ondersteunende aspecten gevonden. Dreigende aspecten waren een tekort aan interesse in dagelijkse activiteiten en een nadelig gevoel tegenover anderen. Dit laatste werd vaker van jongere respondenten gerapporteerd. Verder werden het motiveren van de persoon zelf, het toepassen van coping strategieën en het accepteren van de vermoeidheid als ondersteunende aspecten van autonomie gevonden. In tegenstelling werd het verliezen van de controle als dreigend gerapporteerd. Met betrekking tot verbondenheid werden positieve relaties, communicatie over vermoeidheid en met anderen betrokkenen over vermoeidheid praten als steunend ervaren. Dit laatste aspect werd alleen bij de oudere patiënten gevonden. Anderen niet met zijn vermoeidheidsklachten te belasten en terugtrekken van sociale activiteiten werden vervolgens als dreigende aspecten beschreven. Anderen niet te belasten werd weer alleen bij ouderen respondenten aangegeven.

Discussie: Gebaseerd op de resultaten van de studie kan geconcludeerd worden dat de drie basisbehoeften van de zelfdeterminatie theorie inzicht in het omgaan met vermoeidheid geven. De gevonden aspecten zijn geschikt om een management programma voor RA patiënten te ontwikkelen om in de toekomst nog beter met vermoeidheid om te kunnen gaan.

Abstract

Introduction: Within the symptoms of rheumatoid Arthritis (RA), patients report undergoing extreme fatigue which differs from normal tiredness in being more exhausting and occurring abruptly. To function better in daily life, patients use coping strategies as prioritizing or planning their day. Looking at optimal functioning from a theoretical point of view, the self-determination theory provides for an explanation. It states that if competence, autonomy and relatedness are fulfilled, psychological well-being will take place which underlies optimal functioning.

Method: The current study described the three basic needs competence, autonomy and relatedness as (de)motivators for dealing with fatigue. In a semi-structured interview, 13 RA patients (mean age = 47,62) who experienced fatigue were interviewed individually. Participants were split into two age groups, younger (range = 22-34) and older (range = 50-79) participants to compare the emergence of basic needs. The interviews were analyzed with a mixed top-down and bottom-up coding scheme.

Results: It was found that both undermining and supporting aspects exist, which influence daily life. With respect to competence, supportive aspects were described as knowing where fatigue comes from and being confident about the future improvement of fatigue. In contrast, feeling no drive at all and feeling disadvantaged compared to others were investigated as undermining aspects. The latter was more often reported in younger participants. Regarding autonomy, it was discovered that pushing oneself forward, applying coping strategies and to accept fatigue as a part of oneself support the pursuit of this basic need. Loss of control due to fatigue was explored as an undermining aspect. Moreover, relatedness was supported by positive relations, communicating about fatigue and talking with people having the same symptoms. This last aspect was only found in the group of older respondents. Not bothering others and retreating were found to threaten the pursuit of autonomy. Again not bothering others was only found in older participants.

Discussion: Regarding the results of the current study, it was concluded that the investigation of basic needs provided for a helpful insight into the handling of fatigue in RA patients. The found aspects can be used to establish a management program targeting the handling of fatigue in daily life.

Introduction

Rheumatoid Arthritis

The number of patients diagnosed with rheumatoid Arthritis (RA) has intensely risen in the last decade (Alamanos & Drosos, 2014). In Germany approximately 0,8% suffer from RA in a population of 81 million people (Robert-Koch Institut, 2010). That makes it a total number of 648.000 RA patients. Mostly, RA is associated with higher age but it can occur in all age groups (Rincón, Williams, Stern, Freeman & Escalante, 2001). Contradicting this stereotype, actually 61% of patients with RA are younger than 65 years (Het Reumafonds, 2015).

Symptoms RA patients suffer from are morning stiffness in and around joints, soft tissue swellings and pain due to swellings in such joints (Arnett et al., 1987). As a result of these symptoms, patients have to face adjustments to their life regarding, for example, their leisure, sports and working environment. The disease is therefore not only an alteration in one’s personal life but also for the patient’s environment.

Due to the great occurrence of RA, there is a certain impact on society: next to their disease, patients have to concentrate on their work which results in a daily double load. Consequently, patients are less productive at work (Manocchia, Keller & Ware, 2001). Furthermore, chronically ill patients have a higher percentage of absenteeism at work due to health issues (Vendrig, Hove, Meijel & Donceel 2011). RA patients also face limitations regarding social roles in society, for instance not being able to handle household tasks or personal care (Verbrugge & Juarez, 2006).

Symptoms

RA is an autoimmune disease of an unknown origin (Covic, Adamson & Hough, 2000). More specifically, the body works against itself by producing antibodies attacking its own tissue.

Subsequently this leads to tissue destruction (Lleo, Invernizzi, Gao, Podda, Gershwin, 2009) which shows in episodic and painful joint inflammations that result in swellings (Nielen, 2004). The short term consequence is immobility and discomfort and it can lead to abrasion in the joint structure in the long run (Nielen, 2004).

Considering the course of the disease, patients are not constantly restricted by the symptoms of the same impact, because the disease emerges episodically (Het Reumafonds, 2015). That is to say, patients are in some periods more limited by the symptoms than in others. Therefore, the disease can in metaphorical terms be described as proceeding wavelike. Consequently, patients do not only live with current pain and limitations, they also face future restriction of movement. The psychological stress in this context is therefore bilateral: the discomfort going along with the symptoms in the present on the one hand and the anxiety of symptoms occurring in the future on the other hand.

Having mentioned the psychological and bodily factors, it is not astonishing that rheumatoid arthritis is also considered to be a psychosomatic disease (Klußmann, 2013). Psychological factors therefore interact with the signs of RA and may improve or worsen the symptoms. Consequently, by having an insight into the psychological processes, one can use that knowledge to weaken the symptoms of RA. In the study of O'Leary, Shoor, Lorig and Holman (1988) for instance, the instruction of self-relaxation, cognitive pain management and goal setting was positively associated with less pain and joint inflammation.

Lastly and in addition to the mentioned aches and pains, patients also report suffering from joint deformation as a result of repeated inflammations and they often have to cope with comorbidity of anxiety and depression (Manocchia, Keller & Ware, 2001; van Eijk-Hustings et al., 2012). Along with these symptoms, patients undergo extreme fatigue, which is experienced as equally drastic as the main symptom of pain (Nikolaus & van de Laar, 2011).

Fatigue

Approximately 50-80% of RA patients have clinically relevant or high levels of fatigue (Pollard, Choy, Gonzalez, Khoshaba & Scott, 2006). In contrast to normal tiredness, fatigue in RA patients is more extreme, tremendously exhausting and may occur abruptly which makes it difficult to foresee (Nikolaus, 2012). Until now a clear definition of RA fatigue has not been assigned (Hewlett, Hehir & Kirwan, 2007). However, there are patient reports of the different symptoms of fatigue. Most patients perceive it as multidimensional (Magnusson, Moeller, Ekman and Wallgren, 2001): patients refer not only to the physical impact of fatigue but to emotional and cognitive levels as well (Nikolaus & van de Laar, 2011).

Recent research describes that pain, physical functioning and depressive mood all influence the extent to which fatigue is present in RA patients (Nikolaus, Bode, Taal & Laar, 2013). The relation which is especially described is the one between a bad mood and high levels of fatigue (Matcham, Ali, Hotof & Chalder, 2015). Additionally, studies found out that higher daily activity levels were related to lower fatigue levels (van Zanten, et al., 2015; Rongen-van Dartel et al., 2014).

As far as causality is concerned, it is not quite clear where fatigue has its origin: it might be related to inflammation activity, pain, poor sleep (Hewlett et al., 2005) or psychosocial factors, such as struggling with the fulfillment of social roles (Huyser et al., 2004). In their study, Nikolaus, Bode, Taal and Laar (2010) found out that "patients with multiple roles (e.g. housekeeping, working, being a spouse, parent) seemed to live in a constant tension between the adequate fulfillment of their roles and the need for rest or relaxing activities" (Nikolaus, Bode, Taal and Laar, 2010, p.2196). The management of daily life is hence experienced as difficult and imbalanced (Feldthusen, Björk, Forsblad-d'Elia, Mannerkorpi, 2013. In order to cope with their illness better, patients use strategies as: conscious self-care, mental strategies, planning and prioritizing (Feldthusen, Björk, Forsblad-d'Elia and Mannerkorpi, 2013).

Due to the use of such strategies, patients can function better in daily life which means an enormous enrichment and improves their life quality (Feldthusen, Björk, Forsblad-d'Elia and Mannerkorpi, 2013). Investigating aspects of individual functioning, the self-determination theory (Ryan & Deci, 2000a) offers explanations for RA patients with fatigue. It describes effective aspects regarding optimal functioning in terms of motivation. Due to this theoretical framework it is possible to examine under which conditions RA patients are motivated to deal with fatigue.

Self-determination theory

The self-determination theory (SDT) explains human behavior in terms of extrinsic motivation (influenced by external rewards) and intrinsic motivation (influenced by internal rewards) to explain active or passive engagement in activities (Ryan & Deci, 2000b). For an action to be intrinsically motivated and thus self-determined, the SDT portrays three fundamental needs which have to be fulfilled: (1) competence, (2) autonomy and (3) relatedness (Ryan & Deci, 2000a).

First of all, competence describes one's resources of capacities to perform action (Deci & Ryan, 2002). In literature competence is often split into the (1) actual resources of one's capacities or the (2) perceived resources. The latter is described as self-efficacy describing one's own beliefs in being able to show a certain behavior (Gist, 1987; Ryan & Deci, 2000b). In the following, the first definition is used. Regarding qualitative research, Rosenkranz, Wang and Hu

(2015) discovered the motivation among medical students to do research. In their study competence was supported by being confident about the research topic. Schnall, Bakken, Rojas, Travers and Carballo-Dieguez (2015) found in their research about HIV patients that competence showed in being able to manage the chronic disease. Thus self-management had a positive influence on the experienced competence. These findings may also be adapted to the target group of RA patients with fatigue, namely: being confident about the development of fatigue and being able to self-manage fatigue.

Secondly, autonomy is defined as the independence to perform one’s action (Williams, McGregor, Zeldman, Freedman, Deci, 2004). It is thus essential that individuals experience behavior as a result of an intrinsic decision (Dickinson, 1995). At the same time they should not be restricted by the environment (Ryan & Deci, 2000b). Autonomy is above all portrayed in being able to schedule one’s own time and thus being able of self-management (Rosenkranz, Wang and Hu, 2015). Another important point is that the individual feels to be in control (Schnall, Bakken, Rojas, Travers & Carballo-Dieguez, 2015).These components might also be suitable for RA patients with fatigue. As already mentioned above, self-management strategies lower the limitations of RA patients’ daily life (Feldthusen, Björk, Forsblad-d’Elia and Mannerkorpi, 2013).

Relatedness is the third of the three fundamental needs. It refers to the experience of feeling connected with others or in other terms of feeling a “sense of belonging” (Niemiec & Ryan, 2009, p.139). This experience can be supported by a warm, caring and respecting environment (Niemiec & Ryan, 2009), for example by surrounding yourself with positive people or in case of chronically ill patients by looking for the company of those having the same disease (Schnall, Bakken, Rojas, Travers & Carballo-Dieguez, 2015).

The SDT states that if all three needs are fulfilled, motivation is intrinsic (coming from the inner values of an individual) and forms the basis for psychological well-being (Ryan & Deci, 2000a). Due to this, individuals can grow, be creative and explore new capacities without the need of external reward (Ryan & Deci, 2000a).

With regard to interventions, SDT is often used to support health behavior. In their study Williams et al. (2006) tested a SDT intervention in behavior change for tobacco cessation. The experimental condition was guided by more autonomous attendance compared to the control condition which showed in greater cessation and in turn to greater abstinence in the long run. For the present study, this means that supporting autonomy might lead to a continuous implementation of healthcare behavior regarding RA fatigue. Rongen van Dartel et al. (2014) and Rouse (2014), for example, supported autonomy in an intervention with regard to daily activity in RA patients to decrease the level of fatigue. Acknowledging this finding, a healthcare intervention which focuses on physical activity among pupils is portrayed by Chatzisarantis and Hagger (2009). This study presents similar results: pupils taught by autonomy-supporting teachers had greater interests in physical activity and participated more frequently in it than the control condition. Hence, both the intention to perform action and the continuous implementation of it was supported by the fulfillment of autonomy. Regarding the target group of RA patients, the intention to implement fatigue-improving behavior and to keep implementing it in the long run could be achieved when autonomy is supported.

When it comes to age differences within the SDT, Weman-Josefsson, Lindwall and Ivarsson (2015) found in their study that older adults were more autonomous in exercise behavior in an e-health program compared to younger adults. Another study by Heller et al. (2011) describes that self- determination in general increases throughout adulthood. Furthermore, the individual development is according to them positively influenced by a supporting family or stimulating school environment.

Present study

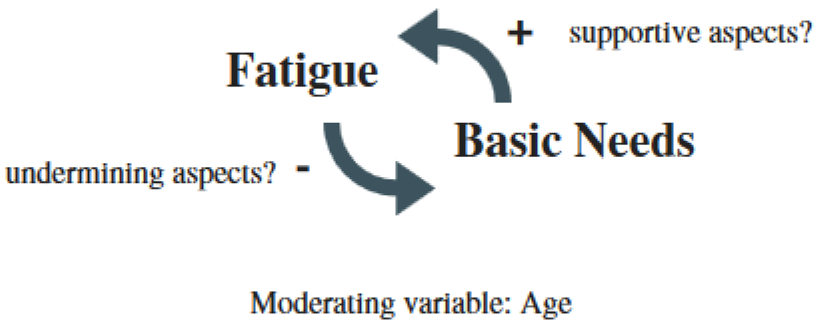
Having described the struggles in daily life due to fatigue in RA patients, there is a need for “psycho educational and management strategies that specifically target fatigue as part of an overall rheumatoid arthritis management program” (Franklin & Harrell, 2013, p.203). Additionally, fatigue in younger populations has not been much explored yet (Franklin & Harrell, 2013). An intervention considering the handling of fatigue is therefore needed. To investigate how patients deal with fatigue, it is essential to comprehend fatigue from a patient’s perspective. Due to the discovery of a patient’s point of view, supportive and undermining aspects regarding the handling of fatigue can be examined. Moreover it is necessary to understand their subjective estimation of the relation between fatigue and basic needs to either improve undermining aspects or to introduce the assistance of supporting aspects in a rheumatoid arthritis management program. This fundamental knowledge is needed in order to help RA patients with fatigue in the best possible way. In the context of SDT, the target group of RA patients with fatigue has not yet been investigated and is thus analyzed in the current study. Subsequently it is evaluated weather the SDT is applicable to this target group.

It also gets clear that there might be an age difference when it comes to basic needs, especially regarding the pursuit of autonomy. Age might thus portray a moderating variable. Due to the qualitative nature of the current study it is possible to get an insight into both younger and older patients’ perspectives regarding the importance of different basic needs. For a better representation, the described assumptions about the constructs are presented in a heuristic model (Figure 1). Taking all this into consideration, the following research questions were investigated:

1. **How do RA patients describe the relation between basic needs and fatigue?**

2. **To what extent does this relation differ between age groups?**

Figure 1. *Heuristic model of the relationship between the constructs fatigue, basic needs and age*



Method

Design

The current study is a reanalysis of the studies of Dermer (2015) and Thieler (2015) who explored different coping strategies, communication and the role of illness perception with regard to RA fatigue. The sample consisted of German participants with the average age of 56 years (SD = 15,76). As not all of the participants gave permission to reanalyze their data, 10 out of the 16 interviews will be analyzed. In addition to their sample, three younger participants are added in the current study to be able to compare age groups.

Members of the German Rheuma Liga (and thus patients of RA) were invited in an official letter to participate in the study. The letter contained a flyer with a description of the study (Appendix I). After one week, they were called and asked if they wanted to participate in the study. The three additional participants were approached via social networks. All interviews were made face-to-face at the participants' homes, except for one which had to be done by phone because of the great distance between the researcher's and the participant's place of residence. For a later transcription the interviews were recorded.

Participants

A German sample of 13 participants with the average age of 47,62 (SD = 19,52), ranging from 22 to79 was used in the study. Among them there were 1 male and 12 female participants. The disease duration had a great variety, from 1 to 43 years with an average duration of 17,08 years (SD = 12,71). With respect to the educational level the sample was broadly ranged: from secondary school till Master of Science. Additional characteristics are presented in Table 1. One participant (nr. 5, woman, 79) was excluded from the analysis due to insufficient information about aspects of the basic needs. The analysis was thus based on the interviews of the 12 remaining participants.

Table 1. *Demographic data*

Variable	**N**	**Mean**	**Range**	**Standard Deviation**
Age	13	47,62	22 - 79	19,52
Illness' Duration	13	17,08	1 - 43	12,71
Sex				
Female	12			
Male	1			
Education				
Secondary school	8			

University degree	5
Work situation	
Student	3
Working	4
Further education	1
Pension	2
Invalidity Pension	3
Marital Status	
Single	7
Married	4
Widowed	1
Divorced	1
Living situation	
Alone	2
With family	5
Flat-sharing community	6
Taking medicine on a regular basis[1]	10
Comorbidities	
High blood pressure	2
Migraine	1
Diabetes	1
Asthma	1
Thyroid disorder	1
Uveitis	1
In treatment by rheumatologist	11
Other treatments	
Physiotherapy	3
Homeopathy	2
Accupunture	1

[1] question: Do you take medicines on a regular basis? Answer: Yes/No

Interview

The semi-structured interview (Appendix III) mainly contained open questions. Closed questions (containing explanatory examples) were added if a question was not clear to the participant. Throughout the interview the following topics were examined: (1) Demographic Data; (2)

General information about the participants' RA fatigue (e.g. subjective experience), (3) subjective origin of RA fatigue, (4) consequences of fatigue, (5) time line of their fatigue (e.g. the first time fatigue occurred), (6) coping with fatigue and (7) communication about fatigue with professionals and social environment. An overview regarding the topics and corresponding questions can be found in Table 2.

At the beginning of the interview, participants had to read and sign an informed consent (Appendix II) in which they received a broad description of the study and in which they were also informed about their right to withdrawal from the study at any moment. Subsequently, the interview started. During the interview, every participant received the same standardized questions in order to provide an equal information supply. If a question was unclear, it was formulated differently. At some points the participant was asked to detail the statement or to give examples. In case a later question was already answered in an earlier question, the order of the topics was changed. In the end, participants were given the possibility of making annotations.

Table 2. *Overview interview topics and exemplary corresponding questions*

Topic	**Examples**
(1) Demographic Data	E.g. How old are you? How long have you been suffering from RA?
(2) General information about RA fatigue	E.g. How do you experience RA fatigue?
(3) subjective origin of RA fatigue	E.g. What do you think is the origin of your fatigue?
(4) consequences of fatigue	E.g. How does fatigue affect your life?
(5) time line of their fatigue	E.g. Would you classify your fatigue as chronic, episodic, acute or otherwise?
(6) coping with fatigue	E.g. Do you use certain strategies to cope with your fatigue?
(7) communication about fatigue with professionals and social environment	E.g. Do you feel able to talk about your fatigue?

Analysis

After the interviews were transcribed verbatim, they were analyzed by use of the qualitative data software Atlas.ti. The advantage of using Atlas.ti is that adding codes directly, forming categories and connecting different topics make the analysis process visible to the user (Paulus & Lester, 2015) and thus improve the progression of the analysis. With respect to the analysis a mixed top-down (codes about competence, autonomy and relatedness were taken from former studies) and bottom-up (the patients' own codes about competence, autonomy and relatedness were investigated during analysis) coding scheme (Appendix IV) was developed. The data were exclusively coded with respect to competence, autonomy and relatedness. The focus thus led on the interview parts relevant to answering the research questions.

The coding scheme regarding the basic needs in RA patients with fatigue was inspired by the qualitative studies by Rosenkranz, Wang and Hu (2015) and Schnall, Bakken, Rojas, Travers and Carballo-Dieguez (2015). The first study explored the motivation among medical students to do research using the SDT. As the current study has patients with a chronic disease as target group, the latter study was consulted to get more inspiration from a pathological point of view. Schnall, Bakken, Rojas, Travers and Carballo-Dieguez (2015) used the SDT in combination with an e-mental health approach to investigate the needs of HIV positive patients. Exerting these two studies as an inspiration, the following codes were explored in a top-down process: (1) competence was portrayed in *structured activity* and *confidence* (2) autonomy was displayed by being able to *schedule one's time*, being *in control* and *self-management* and (3) relatedness was characterized by *social activities*, *positive relationships* and meeting *people with the same disease*. During the analysis the codes were changed or adjusted, which led to the final coding scheme: (1) competence was portrayed by being certain about one's *fatigue's origin, being* *confident*, *disadvantaged compared to others* and *torpidity;* (2) autonomy was investigated by *striving for independence, task-related coping, acceptance, being overwhelmed by fatigue* and *limitation*; (3) relatedness was investigated by *positive relations, communication about fatigue, people with the same disease*, *retreating and not bothering others.* The definite coding scheme is assembled in Table 3. After the seventh interview no new codes were added and saturation was reached.

Table 3. *Overview definite coding scheme*

Competence	**Autonomy**	**Relatedness**
Fatigue's origin	Striving for independence	Positive relations
Being confident	Task-related coping	Communication about fatigue
Disadvantage towards others	Acceptance	People with the same disease
Torpidity	Overwhelmed by fatigue	Retreating
	Limitation	Not bothering others

In order to compare age groups the sample was divided into two groups: group A ranged from 22 to 34 years (N=5), group B contained 50 to 79-year-old participants (N=8). The division was made after examining the clear age gap of 16 years between participant 5 (34 years old) and participant 6 (50 years old) in this sample. Subsequently, the difference between the two age groups regarding the basic needs was described by creating a table in which the distribution of the different codes and the corresponding basic needs were shown. The comparison between the age groups was made quantitative by counting the incidence of the different codes.

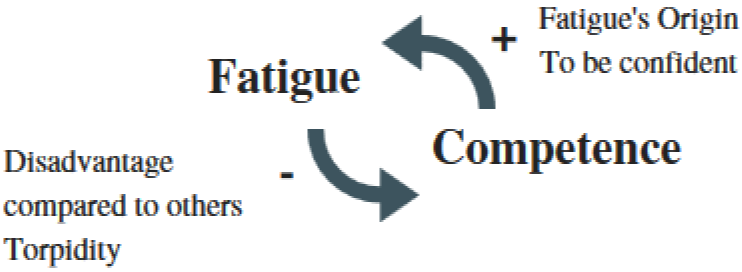
To check for the objectivity of the codes, two researchers coded two randomly chosen interviews independently. Due to this method the personal influence of the researcher was minimized by comparing the two codes and finding an agreement between them. Researcher 2, for instance, was confused by the code *structured activity* and *being able to schedule one's time*, whereupon the definitions of these codes were adjusted. The codes *being able to schedule one's* *time* and *being in control* were also difficult to differentiate. Subsequently the code *being in control* was split into *striving for independence* and *task-related coping* which made the codes better distinguishable. The final coding scheme was approved by the second researcher. Subsequently all interviews were coded with the revisited coding scheme by the researcher of this study.

Results

How do RA patients describe the relation between basic needs and fatigue?

Competence

Figure 2. *Overview Results: Competence*



Concerning the subject of competence the codes *fatigue's origin* and *confidence* were found which were reported to be supportive. The codes *disadvantage towards others* and *torpidity* were found which comprise the pursuit of competence.

Table 4. *Definition Code 1*

Nr.	Code	Definition
1	Fatigue's Origin	The person has a convincing idea of the individual origin of fatigue.

Fatigue's Origin. Regarding their fatigue's origin, the participants describe their personal ideas of what they think where RA fatigue has its origin. Actually every participant had an idea of his or her fatigue's source. Most of the participants attribute it to the medicine they take.

"I assume that it [fatigue] comes from the medication I take. I'm not only taking anti-rheumatic medicine but Lyrika for the pain as well. And this one is tremendously inhibiting the state of being awake." (Participant 5, woman, 50)

Another estimated origin was the body condition, that is to say that the body has low parameters, for instance low iron and vitamin D/B12 levels in the blood or has high inflammation levels.

"For example when one has a lack of iron. I have this too, that's where the fatigue is coming from." (Participant 6, woman, 62)

"...I took iron for a while, but especially vitamin D and vitamin B12,[and] I noticed that I am more awake..." (Participant 12, woman, 26)

"I had this [state of fatigue] especially when my inflammation parameters were very high." (Participant 2, man, 75)

Because of the immune-suppressive character of RA, one participant believed that fatigue comes from the overload of the immune system.

"Where does according to you the origin of fatigue lie?
Due to the rheumatic disease, the immune system is dulled."(Participant 7, woman, 50)

Table 5. *Definition Code 2*

Nr.	Code	Definition
2	Being confident	The person is confident that there is a way to manage fatigue in the future.

Being confident. With respect to confidence, participants had different hopes for the future symptoms of fatigue. These hopes were, for instance, related to taking less medicine which conversely would lead to less fatigue.

"I am hoping that it [the medicine] is going to function better so that I can take fewer painkillers. Because that's related to it [the fatigue], and I would be less tired then." (Participant 5, woman, 59)

Another hopeful appraisal of the future was related to research to handle fatigue. On the one hand it was stated in context of conventional medicine, on the other hand patients refer to alternative processes, such as psychological treatment without medicine.

"But medical science is so much advanced today. I believe and I hope that there is a way [of treating fatigue]." (Participant 10, woman, 50)

"I can imagine that there is a way in the alternative section to feel more awake. Because I believe that regarding RA fatigue…that one can do a lot psychologically." (Participant 12, woman, 25).

In other statements, participants took the initiative in their confident idea of the future. They searched for new possibilities of handling fatigue themselves or they had a clear plan what to do if fatigue worsened in the future.

"So that is why I'm actually always searching. What it [fatigue] could support and what one can do in the context of what is possible." (Participant 8, woman, 26)

"Maybe it [fatigue] returns again, but then I do know how to handle it…the body has a problem then, and the problem is hence solved." (Participant 11, woman, 25)

Table 6. *Definition Code 3*

Nr.	Code	Definition
3	Disadvantage compared to others	Feeling restricted in comparison with others.

Disadvantage compared to others. Some patients have a sense of not being able to accomplish situations as well as others. This is caused by both everyday situations as well as situations in which participant have to perform highly. In some cases, this is related to a feeling of uselessness that arises in this context.

„In such a moment [when doing house holding tasks] one is feeling pretty useless. Just according to the motto 'you did accomplish a lot now, but others would have accomplished a lot more in this situation compared to you. And you are already tired by now.'" (Participant 3, woman, 53)

In line with this statement, other participants report pressuring themselves to be as good as other people.

"How would you describe your feelings towards fatigue?
(…) Actually I have to… I'm seeing other people and…and I have to perform what others are able to perform."(Participant 8, woman, 26)

When reporting about people of the same age, patients especially feel disadvantaged and try to suppress the feelings of fatigue to be able to participate in suggested activities.

"…when others in my age (or my younger sister) say "we are going to party", [and] one is exhausted, one tries to suppress it [and] tries to take part anyway."(Participant 10, woman, 34)

Lastly, participants state that the handling of their daily life has a greater impact on them because due to fatigue they are exhausted faster than other people.

"Well, I do notice it, that daily life, when I'm a lot on the road (...) it is more exhausting for me than for others." (Participant 12, woman, 25)

Table 7. *Definition Code 4*

Nr.	**Code**	**Definition**
4	Torpidity	Feeling torpidity as a result of fatigue and not doing the task that was planned.

Torpidity. As a result of fatigue, participants report feeling a form of torpidity. That shows in not wanting to do anything, having no motivation or postponing tasks to the following day. Additionally participants report not being able to concentrate and having a lack of interests when fatigue is present.

"Yes for example that you lack motivation to do something. Or (...) if there is something to do in the garden [I say to myself]'Oh I can do that tomorrow as well'" (Participant 2, man, 75)

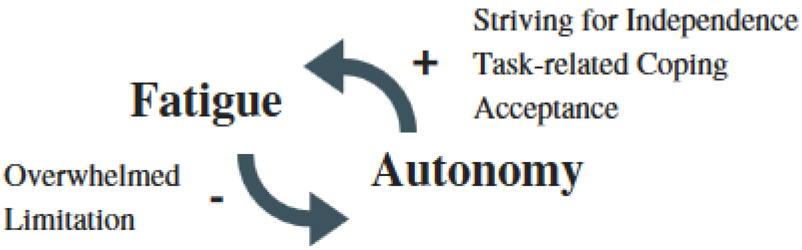
"I can concentrate worse for example. And also [I suffer from]a little bit of a lack of interests." (Participant 9, woman, 22)

Torpidity is also defined as the need of lying in bed all day long and having no drive to do anything.

"You just have the feeling that you just wanna lay around and then you can't do anything. You have no incitement then." (Participant 3, woman, 53)

Autonomy

Figure 3. *Overview Results: Autonomy*



With respect to autonomy the codes *striving for independence*, *task-related coping* and *acceptance* were found which were reported to be supportive. The codes *overwhelmed by fatigue* and *limitation* were found to comprise the pursuit of autonomy.

Table 8. *Definition Code 5*

Nr.	Code	Definition
5	Striving for independence	The person pulls through with the exercises to do in spite of fatigue.

Striving for independence. With respect to their striving for independence in RA fatigue, patients give different statements. To begin with, they say that one has to get the best out of one's situation and that one should not sit back and take things easy.

"You have to get over a lot of things and try to make the best out of fit. You should not sit back and take things easy." (Participant 2, man, 75)

Others phrase it a bit differently. They say that they are in charge themselves of getting the best out of the situation. Consequently they are taking an active role in handling their fatigue and determine themselves how to handle a situation.

“I take a break and afterwards I continue again (...) I see it as positive and try not to see it too emotional (…) I do not want to leave so much room for my illness.” (Participant 5, woman, 50)

Some participants state that they do not want to abstain from things which leads to the motivation of pulling through.

“On the other hand I do not want to abstain from something. I then pull myself together and do different stuff. It is very important for me not to suffer from a disadvantage or to feel handicapped.” (Participant 8, woman, 26)

One participant reported that due to her pain and the resulting higher levels of fatigue she was advised to take stronger medicines. But she fears missing out on things happening in her life because of the side effects the stronger medicine would have. That is why she is now pushing herself forward, so that she does not have to take these medicines.

“I just take light painkillers because I say to myself: somehow I gotta go through that. I do not want to use morphine patches, become tired and fall asleep. This is not a solution. I gotta go on.“ (Participant 7, woman, 50)

Table 9. *Definition Code 6*

Nr.	**Code**	**Definition**
6	Task-related coping	The person arranges his activities in a way to better cope with fatigue.

Task-related coping. Participants report applying a range of task-related coping strategies in their daily life to deal with fatigue. One of them is to rest at noon.

“(...) I arrange the day in a way that I have at least a one hour break every noon.” (Participant 1, woman, 59)

There are also participants who are taking caffeine, e.g. in the form of an espresso or pills.

"*Every time when I am coming home, I drink an espresso." (*Participant 4, woman, 59)

Other strategies that were investigated are physical exercises to inhibit fatigue, like going out for a walk or bicycling.

"Sporting activity is very important, to ride a bicycle or to go for a walk for example. Being a couch potato is no solution.“ (Participant 4, woman, 59)

A completely different strategy which was presented by one participant is meditation. She states that it is especially efficient when meditating in the morning because it has a positive influence on her concentration. A few participants also state that relaxing activities would help to handle fatigue.

"I meditate daily. I 'm doing a meditation course these days. It is very effective, I must say. Especially in the morning. I can feel that it has a positive effect on my ability to concentrate." (Participant 9, woman, 22)

"(...) [It helps a lot when I am] doing Yoga, relax a lot and try to escape from daily life." (Participant 10, woman, 34)

At last, some participant use the strategy of ignoring fatigue and just going on with their tasks.

"Sometimes I just ignore the fatigue and continue with my daily routine." (Participant 11, woman, 25)

Table 10. *Definition Code 7*

Nr.	Code	Definition
7	Acceptance	Seeing the disease and fatigue as part of yourself.

Acceptance. Referring to the acceptance of fatigue, participants have different ways of accepting their situation. One participant states that she does not even think about being tired.

"You don't think anymore. It's just a part of you, like your pocket or your cell phone. Or your glasses. That's just like it." (Participant 1, woman, 59)

Another participant reports that it is especially the loss of control that she accepts because that is a circumstance others would overlook and would carry on.

„I see it like you just have to accept your disease even if other people disagree on that… One has to accept that one sometimes has no control… that one sometimes relinquishes it." (Participant 3, woman, 53)

The acceptance of having one's own pace is reported by some participants. Additionally participants think that it is important to take one's time for doing things without being in a hurry.

"… one has one's own workload and actually I learned to accept that and to take the time I need." (Participant 8, woman, 26)

Lastly, one participant reports adapting to the acceptance of fatigue in special situations, e.g. in exam periods. Then she interrupts her learning process and if she cannot concentrate after a break she will stop learning as a way of accepting her situation.

"Actually I accept that [fatigue]. For example, when you have to concentrate when you're in a learning session. Then it [being fatigue] is a bit unfavorable. But then it is just like that and I go to sleep for an hour. I try to go on but when I'm not able to I just leave it alone." (Participant 9, woman, 22)

Table 11. *Definition Code 8*

Nr.	Code	Definition
8	Overwhelmed by fatigue	To feel that fatigue overwhelms the person and that he is no longer in control.

Overwhelmed by fatigue. The loss of control is often reported by participants. This is especially reported as a psychological consequence of fatigue. One participant reports that she has to pore a lot as a consequence of fatigue or sleeping problems. That makes her even more tired but simultaneously she cannot fall asleep.

"[When I am tired I feel] dizzy or that you're pretty busy with it. Then I have that always at night… I'm thinking about it [being fatigued] and that's why I can't go to sleep even if I'm tired but yeah… how can I describe that? You go to bed with that feeling that you're very tired but you cannot go to sleep." (Participant 3, woman, 53)

A few participants report that they feel captive to fatigue. One participant states it even more strongly: the feeling of being captive leads to a depressive mood because she is totally out of control.

"Yes… it [being fatigued] results in a stress situation (…) you feel like being extradited to this whole thing. And there are also „"stress hormones" for example (…) Then it is a stress spiral... It's like falling into a depression…yes I'm kinda extradited and can't do anything against it." (Participant 8, woman, 26)

In line with that statement another participant states that the feeling of being overwhelmed leads to desperation because she cannot perform as she wants to.

"[Being fatigue leads to] incomprehension. Of course when you want to go out but feel that it's not going to happen because you're lacking motivation…it's always a discord. I am really despaired then because I really wanna go out." (Participant 10, woman, 34)

Lastly one participant reports that due to the need of continuing as if she was not tired she feels frustrated. It is not only that she cannot perform as she would like to, the feeling of frustration that guides this process is even more burdening.

„Due to this further burden [fatigue], due to the need of continuing like I previously did, it results in a great frustration… and I would gladly say, that I don't have this feeling of

frustration and that I can handle it well…in a way I can accept that it is a part of me but it is however frustrating." (Participant 12, woman, 25)

Table 12. *Definition Code 9*

Nr.	Code	Definition
9	Limitation	To feel limited in daily life due to fatigue.

Limitation. When it comes to limitation some participants are angry because they cannot be efficient in daily life.

"Do you have additional feelings related to your tiredness?
Ähm…yes, it makes me pretty angry because you are less efficient." (Participant 11, woman, 25)

Additionally, participant cannot take part in their life as they would to like which leads to a general restriction.

"Because you're not so fit you cannot really participate in life. And then I have the feeling that because you can't really participate … you always restrain yourself." (Participant 3, woman, 53)

In line with this finding, participants report being guided by a feeling of weakness and powerlessness.

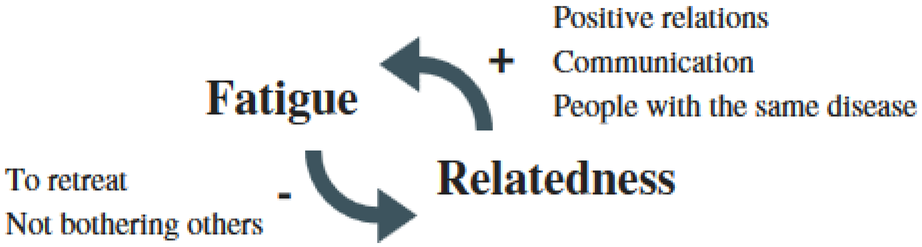
*"Weak I would nearly say... feeble. Yes, it restricts you in your daily life a lot." (*Participant 10, woman, 34)

One participant even states that he feels that fatigue is in the whole body and that he in turn feels handicapped.

"…this tiredness, which is inside of your body, that you are handicapped through it." (Participant 2, man, 75)

Relatedness

Figure 4. *Overview Results: Relatedness*



With respect to relatedness the codes *positive relations*, *communication about fatigue* and *people with the same disease* were investigated to facilitate this basic need. In contrast, *retreating* and *not bothering others* were found to undermine relatedness.

Table 13. *Definition Code 10*

Nr.	Code	Definition
10	Positive relations	The person reports having relationships that enrich him and to whom he/she can go to when feeling like talking about fatigue.

Positive relations. Regarding important relations in their environment, participants report feeling accepted and valued in their social environment. Not only regarding their free time activities but also in their working environment.

"They [colleagues at work] have understanding for it [fatigue]. They know then how long I have rheumatism." (Participant 6, woman, 62)

"And the guys from my skittles club, they already know that it [fatigue] comes from the medicine and done (...) It is just okay that I'm tired." (Participant 4, woman, 59)

Additionally they feel free to talk about their feelings, because they regard the environment of their friends as comforting.

“I have a social environment that supports me completely (...) They always accepted, that I indulge how I feel and they never reproached me for anything…” (Participant 5, woman, 50)

Others report having special contact persons in their family to whom they can go.

„… [I go] to my parents. They know the whole picture [of my disease], because they are clinical experts, they have understanding and want to support me.” (Participant 10, woman, 34)

„…And I report a lot to my mother, how everything is going. How I handle things.” (Participant 8, woman, 26)

“Do you feel able to talk about your fatigue?
Yes, but as I already said not always and all above not with anybody. But sometimes with both of my sisters and I additionally have two friends from my childhood.” (Participant 4, woman, 59)

Table 14. *Definition Code 11*

Nr.	Code	Definition
11	Communication	To feel able to talk about fatigue.

Communication. With respect to the communication about their fatigue, participants state that they communicate about fatigue with different aims. First, they think that it belongs to a friendship to be part of one and another’s life.

“Well we are talking about it very openly, because I think, if you have friends, acquaintances and relatives you should initiate them (...). They are taking part in my life as well. I also want to know what they have.“ (Participant 7, woman, 50)

When going to the rheumatologist, a few participants report that fatigue is a topic during their treatment. Thus they speak to professionals to inform them about their well-being.

"Sometimes Ms. L. [rheumatologist] addresses it and sometimes I do. Or she asks how I am doing, how things are with fatigue. If it is getting better or worse." (Participant 7, woman, 50)

Another purpose when communicating about fatigue is to get advice from others.

"…Or in general that I do not have the energy (…). That is how one can get tips… or it is just…if you talk with people about it (…) you see how they deal with [fatigue]." (Participant 8, woman, 26)

Sometimes the communication about fatigue is used to explain to grandchildren why one cannot do a certain activity with them. In that case communication has the function of explaining behavior.

"Then, I sometimes say 'not today, today I can't'. Because… I have three children in a certain age and grandchildren. Yes, sometimes I tell them 'not now, I have to sleep now' also if they do not understand it." (Participant 2, man, 75)

Table 15. *Definition Code 12*

Nr.	Code	Definition
12	People with the same disease	The person is in contact with other RA patients. This relation is described to be beneficial.

People with the same disease. Participants describe the contact with other people having RA as beneficial for different reasons. One is that patients learn that they are not the only ones with this disease which leads to a collective feeling.

"When I took a cure I realized that there exist more people in my age suffering from RA." (Participant 1, woman 59)

Another reason is to swap information about one's medication.

"…when I meet like-minded people that do also suffer from RA, there is always an exchange of information like asking each other: and what medicines do you take?" (Participant 5, woman, 50)

One participant reports that she has many friends who are diagnosed with RA as well. In a conversation they support each other and emphasize that they are in charge of the disease and not the other way around.

"(...) I have a few friends who also suffer from RA and we see that all a bit positive. So we would always say, it is a disease anyhow but we can handle it. WE can control the disease, not the other way round." (Participant 7, woman, 50)

Table 16. *Definition Code 13*

Nr.	Code	Definition
13	Retreating	The person is retreating from social activity because of the impact of fatigue.

To retreat. Being fatigued leads to a withdrawal from social activity. In some cases patients would make an excuse as a reaction to an invitation. They say that they have no time or that they do not like to go out that day.

"And then you say, no I have no time today. I am not up to it or something like that." (Participant 6, woman, 62)

This leads to a general shortage of spending time with friends in acute phases of fatigue.

"In the acute period I just realize that I often have to make a break that I retire, sleep or simply leave earlier than others." (Participant 8, woman, 26)

"When I had this severe fatigue…I was less positive and I had less time for my friends and my family." (Participant 12, woman 25)

With regard to social activities in the evening, it is difficult for some participants to maintain their sleep hygiene. As a result going out at night happened more rarely.

"And if you go celebrate during the weekend, for example. First of all you do not do that so often anymore…I am thrown out of my sleep pattern then and that is kind of hard." (Participant 9, woman, 22)

In one case the participant reports that she retreated extremely from any social activity when she was younger. She even attributes this to being unmarried today.

*"Then I totally retrieved from anything. That is also why I am unmarried. Because at that time I retrieved extremely." (*Participant 1, woman, 59)

Table 17. *Definition Code 14*

Nr.	**Code**	**Definition**
14	Not bothering others	The person does not talk about fatigue with others because he does not want to reveal how he really feels regarding fatigue.

Not bothering others. When it comes to non-communication about fatigue, participants give different reasons. First, when others state that they are tired participants mention their tiredness as well but do not deepen this topic any further, because others do not do it either.

"Yes, when you talk about it and you say „Oh I am so tired" and then the next one says „oh I am so tired, too" – but you do not talk about it any further. Because it is just like that." (Participant 1, woman, 59)

Others choose not to talk about their fatigue, because when they are with others they want to forget about it and thus keep it out of their mind.

"You cannot explain everything, too. And if I leave the house I do not want to talk about it at all. Because sometimes you just do not want to think about it." (Participant 4, woman, 59)

Another cause of not talking about fatigue is that some participants do not want to be pitied. On the one hand being fatigued is embarrassing for them; on the other hand they cannot stand the feeling of being pitied.

"We do talk about fatigue (…) and then [someone says] 'Oh [name] – that is coming from your disease, or something like that?' That is partly embarrassing for me,… ." (Participant 4, woman, 53)

" …I am vigilant that I am not talking too much about it [fatigue], because nothing is worse [than] being pitied …" (Participant 12, woman, 25)

One participant states that she does not talk about fatigue without knowing any reasons why she does not do so. Simultaneously, she underlines that one does not have to tell everybody about it.

"I do not do that [talking about fatigue]. I do not know why. But I do not need to tell everyone. When I cannot go on any longer, when I am doing a trip, I simply stop. That is the way I see it. I do not need to disclose my illness." (Participant 6, woman, 62)

To what extent does the relation between basic needs and fatigue differ between age groups?

With regard to the age groups, there are no revealing differences observed regarding the peculiarity of different basic needs. The emergence of competence, autonomy and relatedness was approximately equally distributed in both age groups. However some tendencies could be observed.

Referring to competence, every participant had an idea of the origin of his/her fatigue. These ideas did not differ much among the age groups. Both medicine and bodily condition were mentioned mostly as cause of fatigue in both groups.

“I especially had this [fatigue] when my inflammation parameters were very high” (Participant 2, man, 75)

„When it is going pretty bad in phases in which I have so many inflammations, the body has just a lot to do, to [fight against] these inflammations or (...)one is just bodily tired” (Participant 11, woman, 25)

Additionally most of the participants were confident about the future development of fatigue. In group A *disadvantage compared to others* was put forward a little more often by the participants. Three participants stated it from group A and one participant from group B. The effect of feeling disadvantaged resulted in a lower self-esteem in the participants from group B.

“Sometimes you feel like everybody would master his life besides you. The self-esteem is sometimes shit then.” (Participant 3, woman, 53)

In group A, the disadvantage was especially portrayed in coping with one’s daily life.

“Yes, you’re not so mobile in your daily life like others would be in this age.” (Participant 10, woman, 34)

With respect to autonomy, no differences in the distribution of the codes could be observed. Actually, autonomy was the basic need which had the broadest characteristics. That is to say in every interview both supporting and undermining codes were found for autonomy. So this basic need had the broadest variety.

Regarding relatedness, group B participants reported being in contact with other RA patients, whereas none of the participants from group A reported that.

"And I have some acquaintances who have rheumatism too and we all see it a little bit positive." (Participant 7, woman, 50)

Additionally the code *not bothering others* was only found in group B.

"Yes, I also think that I couldn't explain that [fatigue] to them. No. They wouldn't understand it. Often it's just like that, that they don't understand you." (Participant 3, woman, 53)

To sum up, there are two codes which were only found in group B participants: (1) *people with the same disease* and (2) *not bothering others*. In group A, *disadvantage compared to others* was reported more often.

Discussion

The aim of the present study was to describe the relation between RA fatigue and basic needs from a participant's point of view and to investigate possible age differences between two age groups. This study makes considerable progress in the field of RA fatigue as it is the first to study the patient's perspective on the relation between competence, autonomy and relatedness and fatigue which has not been investigated yet.

Concerning the study results, the three basic needs could be divided into aspects which support and aspects which undermine their pursuit. Regarding (1) competence, fatigue's origin was investigated as a lack of vitamin D, B12 and iron parameters or it was attributed to a weakness of the immune system. Future hopes were formulated as taking less medicine which would result in being less fatigued, progressing science and alternative medicine approaches. In group A, feeling disadvantaged was reported more often which in turn was discovered as an undermining aspect of competence. As a result, participants felt useless when accomplishing daily tasks or when returning early from an evening event. Additionally, a lack of interest or having no drive at all was also investigated to threaten competence. Furthermore, (2) autonomy was supported in the sense of not letting RA fatigue interfere too much with daily life. This goal was approached by providing for steps if fatigue occurred or by pushing oneself in difficult situations. Seeing fatigue as part of oneself and having one's own pace was also investigated for backing autonomy. Contrary, threatening factors regarding autonomy were: loss of control; sleeping problems; feelings of desperation, depression or frustration. Lastly regarding (3) relatedness, it was discovered that participants from group A did not mention any contact with other RA patients which group B participants described as supporting. Negative consequences of fatigue on the social environment were also discovered. Withdrawal from meeting friends in times of severe fatigue was investigated in this context. Group B participants also showed that not communicating about fatigue reveals in not being pitied or being able to forget about it.

Due to the descriptive character of this study a first investigation of important factors of the basic needs of the SDT was made as this theory has not yet been applied on the target group of RA patients with fatigue. It was attempted to get an insight into what RA patients consider to be ingredients of competence, autonomy and relatedness. Regarding the results of competence, it was notable that all participants could name at least one cause of fatigue. This finding contradicts the study of Nikolaus (2012) who discovered that fatigue's origin was elusive for RA patients. Having an idea of where fatigue comes from, leads to a good base to work with in an intervention in which new behavior is learned. Thus, fatigue becomes controllable and is not an impalpable phenomenon. Moreover the terms “competence” and “self-efficacy” are used confusingly in literature. Self-efficacy is often referred to as “perceived competence” (Ryan & Deci, 2000; Gist 1987) and is thus defined as one’s belief in one’s capacity to perform action (Gist, 1987). Additionally, the capacity to perform action is comprised in the term competence which the accreditation council for continuing medical education (2016) describes with different components containing knowledge about a certain action as one of them. During analysis the latter was the assumption for coding the patient’s ideas of his/her fatigue’s origin. However, when regarding perceived competence, knowledge would not count as an aspect of it. Future research should take these considerations into account to provide for content validity for competence.

With respect to the aspect of feeling disadvantaged, it was found that group A participants reported it more often. This is in agreement with the study of Kyngäs (2004) which describes that young adults who are chronically ill feel different and socially restricted from their same-aged peers. A possible reason for these findings might lie in modern society. Earlier in this paper it was mentioned that RA patients face social role limitations due to fatigue (Nikolaus, Bode, Taal and Laar, 2010). These social roles have a broad variety nowadays: they reach from an educational and economic context to leisure and outward appearance (Böhme, 2010). Simultaneously the pressure on yielding performances is perceptible (Böhme, 2010). Due to this modern performance-oriented society, younger RA patients might feel the comparison to others more intensively and with more pressure than RA patients who grew up in a different society with different norms. This could also be an explanation for another aspect found in the current study. Younger RA patients did not report being in contact with people suffering from the same disease. Being in contact with fellow sufferers might mean spending one part of one’s leisure with others having the same limitations, which might deflect from the need to perform as well as people without a disease.

Looking at undermining aspects of autonomy, an overwhelming characteristic of fatigue was discovered. This finding is in agreement with fatigue-related literature (Nikolaus, 2012; Hewlett et al., 2005). In these studies as in the current study, it was found that RA patients report being unable to control fatigue, which resulted in desperation and frustration. This might also be a consequence for another pattern found in the current study, namely that due to fatigue, RA patients feel a lack of interest and no drive at all as an undermining aspect of competence. When experiencing this uncontrollable state of desperation frequently it might lead to a dulling feeling in which one loses all interest in doing anything about the situation one is captive in (Hunziker, 2007).

On the subject of supporting autonomy, physical exercise and bicycling were discovered as strategies to reduce fatigue. As RA patients may suffer from swellings in the joints, these strategies are easy to perform as they can be applied to one’s own pace. In their study Feldthusen, Dean, Forsblad-d’Elia and Mannerkorpi (2016) made a supporting discovery: movement had a positive effect on the symptoms of fatigue. Integrating these strategies in a management program would therefore be beneficial to a higher level of autonomy. Furthermore autonomy was also discovered and supported by the self-confidence initiative of participants, enabling them to deal with fatigue. This is in line with the results of Lorig, Chastain, Ung, Shoor and Holman (1989) who found that beliefs in the personal appraisal of daily actions were positively related with self-esteem and thus affected patients with RA positively. This finding can also contribute to support the experience of control as it opposes the sudden and overwhelming character of fatigue. Due to a kind of an ‘emergency plan’ for the occurrence of fatigue, patients may feel more in charge and in control.

Concerning the autonomy-supportive aspect of acceptance the data contained different concepts. On the one hand, participants described acceptance as an actual aim: to accept their disease and all symptoms which belong to it, including fatigue. On the other hand acceptance is described as a means to an end. To be more precise, the condition which underlies the latter phenomenon is that acceptance is seen as a way to deal with fatigue better and therefore used as a coping strategy. In that case, acceptance is linked with an internal pressure, ‘to have to accept’ fatigue to be able to deal with it in one’s daily life. This contradicts the definition of acceptance as it is defined as the ability of unconditionally accepting oneself (Carson & Langer, 2006). Assumedly, patients may be limited in their freedom and in their fulfillment of autonomy when acceptance is characterized as means. If acceptance in the latter case threatens autonomy or if it has to be seen as a way of coping will be an interesting topic in future research.

On the subject of relatedness, it is striking that only participants from group B reported that they avoid talking about fatigue as it is a subject which may result in being pitied or in being misunderstood. In literature, it is also shown that RA patients report the communication about fatigue being difficult due to a lack of understanding from the environment (Feldthusen, Björk, Forsblad-d’Elia, Mannerkorpi, 2013). A main reason for that might be that fatigue is not clearly defined and thus not established in the rheumatoid arthritis-related health care system yet. Consequently, outsiders might confuse it with “normal” tiredness which is relatively easy to deal with and to recover from. They may lack understanding and underestimate the extent of fatigue. Furthermore it has been found out that severe phases of fatigue have a negative influence on meeting friends or maintaining the contact to the social environment in general. This finding is in line with the study by Taylor, Moore, Vasilescu, Alvir and Tarallo (2016) in which approximately one fifth of the RA patients reported the same experience. However, it is shown that social support is a crucial factor in chronically ill patients which influences their well-being positively (Kyngäs, 2004). Therefore it would be desirable to address the social environment in a rheumatoid arthritis management program, especially in times of severe fatigue.

Within the SDT a stimulating social environment of the individual is also seen as inspiring the individual's growth and well-being (Ryan & Deci, 2000a). However, it is not researched in the current study, the social environment could be addressed within a management program based on the SDT as well as it provides for emotional support and being accepted in a community (Kyngäs, 2004). In a management program the patient could, for example, participate with a confidant who takes the role of a mentor as it is suggested by Cohen, Underwood and Gottlieb (2000). During the program the tasks and obligations of the mentor can be prepared with regard to individual needs and with special attention to times of severe fatigue to provide for social contacts in difficult times as well.

On the basis of considering basic needs, the question that still needs to be answered is: is the SDT applicable to the target group of RA patients with fatigue? The results of the current study reveal both supporting and undermining aspects for the three basic needs in RA patients. However, further research is needed, the SDT is considered as a good starting point when regarding the implementation of an RA management program. The current study offers an insight into aspects that support the fulfillment of basic needs and undermining aspects one can address in such a program. In their study Rouse et al. (2014) implemented an intervention for RA patients with fatigue by supporting autonomy in a three month activity program which had positive effects on the decrease of fatigue. Participants from the experimental condition had contact with a supervisor who identified the patient's knowledge about the increased benefit of physical activity in RA, investigated the individual goals and supported attempts to change. These autonomy-supportive techniques were positively related to the implementation of physical exercise. Nonetheless, it would be desirable to refer to all basic needs as they address different aspects and may contribute to a prolonged implementation of behavior.

According to Ryan and Deci (2000a), using the SDT in interventions addresses both the motivation to change one's behavior and fostering personality integration. Within personality integration, the self is described as a motivational process, growing intrinsically by experience, action and relatedness to other selves (Ryan & Deci, 1991). The self can be self-determined when it operates within well-integrated personal values. On the contrary self-determination cannot be reached when behaving according to non-integrated processes, e.g. internal pressure or socially acquired behavior (Ryan & Deci, 1991). In other words, in personality integration a person (the self) only operates within his/her values and his/her personality and is not driven by external expectations. In the current study it was, for example, found out that RA patients have a way of accepting fatigue which in turn supports autonomy. However, especially younger patients report feeling disadvantaged compared to others at the same time as an undermining factor of competence. In a management program this feeling can be approached by integrating all basic needs and by elaborating on personal values in life which would in turn address personality integration.

Limitations

The current study has several potential limitations that might have influenced the results. Firstly, it is a reanalysis of the studies by Dermer (2015) and Thieler (2015). Therefore the interview scheme was planned to answer the research questions of the studies mentioned above. Consequently, the possible findings in this study were limited and may not represent the whole range of the investigation of basic needs. In addition, men (N=1) were represented remarkably less than women (N=12). Even though there are more women diagnosed with rheumatoid Arthritis than men (Kuhlow, 2007), this sample is not representative of the gender distribution. This might have led to a biased investigation of basic needs as women might experience them differently. Furthermore, most of the participants from Dermer (2015) and Thieler (2015) were recruited from the German Rheuma Liga, an association for RA patients. Due to this context, most of the older participants were in contact with other RA patients regularly, which was not reported by the younger participants. Therefore a selection bias might have occurred.

With respect to the interview scheme, the question about taking medicine was a closed question which was answered with yes or no. The regularity of taking medicines might have influenced the experience of fatigue, for instance that patients feel dulled which was shown in the current study. It is therefore advisable for future research to explore the frequency of taking medicines to estimate a possible influence on basic needs.

Lastly, the researcher is a patient of rheumatoid Arthritis herself which might have led to a possible source of bias as well. To counter that, several meetings with the supervisors took place to reflect on the analysis process. Additionally, a second researcher was approached to check on the coding scheme and to minimize the error of the first researcher as much as possible.

Conclusion

This study provides a first approach to the experience of basic needs in RA patients with fatigue. It is shown that there are factors which undermine and factors which support competence, autonomy and relatedness. Between the two age groups, being in contact with other RA patients and not bothering others with fatigue were only found in older participants but not in younger participants. With regard to the self-determination theory it can be concluded that it is suitable for the target group of RA patients. Finally, investigating the basic needs might help RA patients to deal with fatigue better in the future.

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Appendix

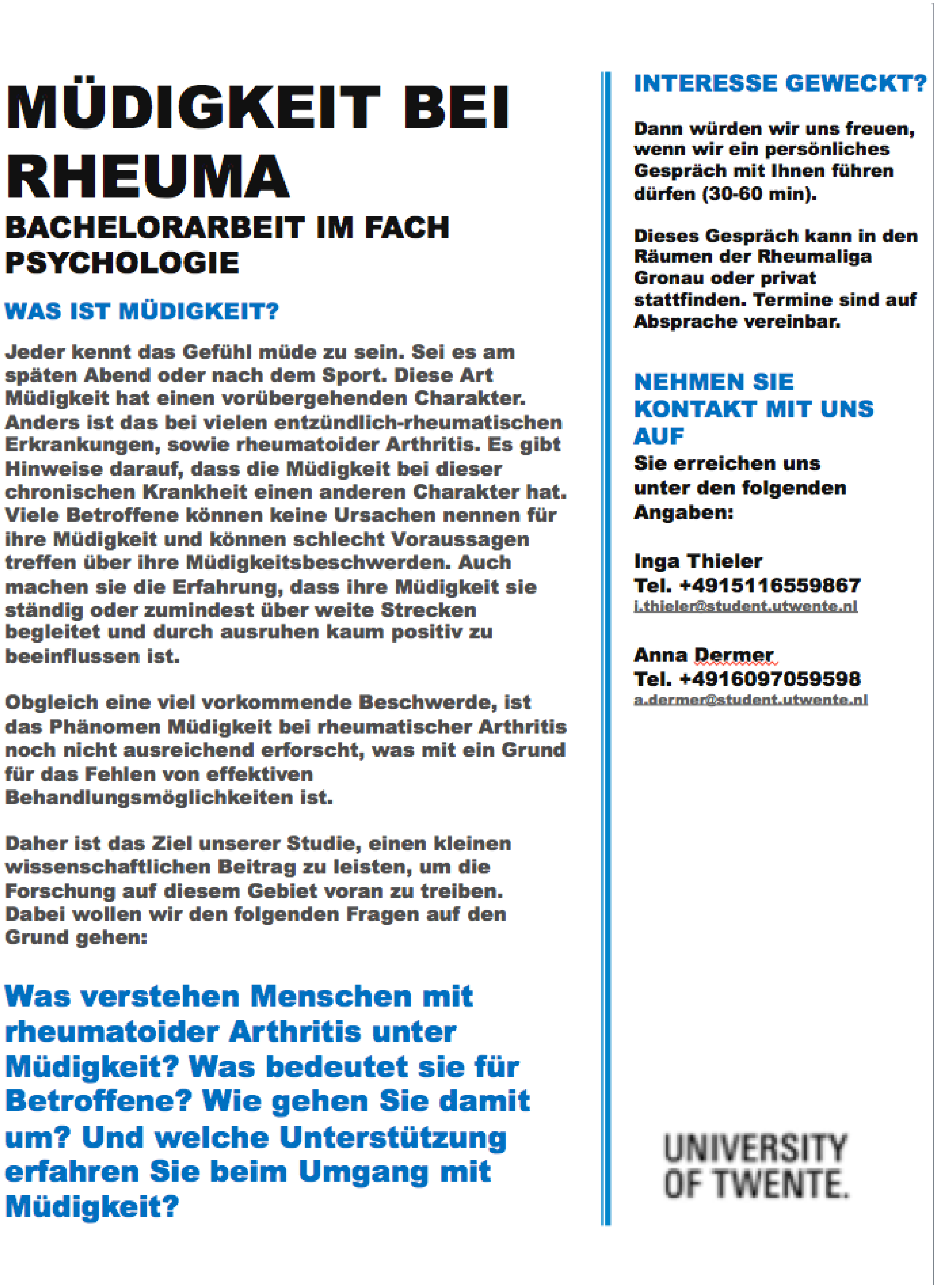
Appendix I – Flyer

Appendix II – Informed consent

Appendix III – Interview scheme

Appendix IV – Coding scheme

Appendix I – 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:

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Appendix II – Informed consent

Informed Consent (German) Melina Gallus, 2015

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

Weiterführende Studie im Bereich RA Müdigkeit

Die Studie deren Daten ich in anderem Kontext analysiere fand ursprünglich im Rahmen einer Bachelorarbeit im Fach Psychologie statt und wurde von den Dozenten Dr. C. Bode und Dr. E. Taal der Universität Twente begleitet. Meine jetzige Studie wird ebenfalls von Dr. C. Bode begleitet. Im Folgenden wird der Inhalt und die Zielsetzung der Studie beschrieben.

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 der Studie besteht darin, Informationen über die Erfahrung von Müdigkeit bei rheumatischer Arthritis zu sammeln. Hierbei wird 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 über das Forschungsvorhaben informiert. 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.

TT-MM-JJJJ, Ort, Name und Unterschrift Interviewteilnehmer

TT-MM-JJJJ, Ort, Name und Unterschrift Untersucher

Appendix III – Interview scheme

’’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.’’

‘‘*Als Erstes möchte ich Ihnen allgemeine Fragen zu Ihrer Person stellen.’’*

1. Demographische Daten

- Geschlecht, nur notieren, nicht erfragen
- Wie alt sind Sie?
- Was ist Ihr Familienstand?
- Wohnen Sie alleine?
- Was ist Ihr höchster Bildungsabschluss?

  Hauptschule (X); Realschule (Sekundarstufe II) (X); Allgemeine Fachhochschulreife (Fachabitur) (X); Allgemeine Hochschulreife (Abitur) (X); Hochschulabschluss (Universität, Fachhochschule); Anderen Schulabschluss (X); Schule beendet ohne Abschluss (X)
- Was ist ihre gegenwärtige berufliche Situation?
  - Berufstätig → Vollzeit/ Teilzeit
  - Frührentnerin
  - Rente / Altersrente
  - Arbeitsunfähigkeitsrente
  - In Ausbildung
  - Hausfrau/ Hausmann
- Welchen Beruf üben Sie zurzeit aus oder haben Sie zuletzt ausgeübt?
  - Berufstätig:
  - Momentan ohne Beruf
- Wie lange leiden Sie bereits an Ihrer Krankheit, in Jahren?
- Gehen Sie zu einem Rheumatologen? Oder nehmen Sie andere Behandlungen in Anspruch?

- Nehmen Sie regelmäßig Medikamente ein?
- Leider Sie an weiteren Erkrankungen neben Ihrer Rheumatoiden Arthritis?
- Haben Sie Schlafschwierigkeiten?

‘’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 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?’’

2. Identität

- 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?
  - 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 im Bezug auf diese eben beschriebene Müdigkeit?
    - Und früher?
      - **Hilfe:** Wie würden Sie Ihr Gefühl darüber beschreiben?

- 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? Wenn ja, welche?
    - Wie erfahren Sie diese?
    - Was unterscheidet sie von einander?

‘’Vielen Dank. Nun möchte ich Sie gerne zu Ihrer persönlichen Einschätzung über die Ursachen Ihrer Müdigkeit befragen. Hier geht es nicht um Medizinisches Fachwissen oder ähnliches. Mich interessiert wie Sie persönlich darüber denken.’’

3. Ursachen

- Menschen haben Ihre eigenen Vorstellungen davon, was ihre Müdigkeit verursacht. Wo liegen Ihrer Meinung nach die Ursachen für Ihre Müdigkeit im Rahmen ihrer Erkrankung?

‘’Vielen Dank. Im Folgenden möchte ich auf eventuelle Auswirkungen eingehen, welche Ihre Müdigkeit auf Ihr Leben hat.“

4. Auswirkungen

- Wie beeinflusst Ihre Müdigkeit, die Sie als Folge von RA erfahren, Ihr tägliches Leben?
    - **Wenn nur auf negative Auswirkungen eingegangen wurde:** Könnten sie auch positive Einflüsse auf ihren Lebensalltag benennen?
    - Wie wirkt sich Ihre Müdigkeit auf das Leben anderer aus?
- Wie stark erfahren Sie die Auswirkungen, welche die Müdigkeit auf Ihr Leben hat – auf einer Skala von 1 (beeinflusst mein Leben gar nicht), bis 10 (hat starke Auswirkungen auf mein Leben)

‘’Vielen Dank. Als nächstes möchte ich Sie zu dem Verlauf Ihrer Müdigkeit befragen.’’

5. Time Line

- Erinnern sie sich, wann ihnen diese Form der Müdigkeit zum ersten Mal bewusst wurde?
    - 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?
    - Wird sie sich verändert haben?
    - Denken sie: Wird sich diese Form der Müdigkeit ihr weiteres Leben begleiten?

‘’Vielen Dank. Ich möchte nun darauf eingehen, welche Methoden bzw. Strategien Sie nutzen um mit Ihrer Müdigkeit umzugehen und wie Sie selbst über Ihre Möglichkeiten dies bezüglich denken.’’

6.Selbstwirksamkeit und Bewältigung

- Wie gehen Sie mit Ihrer Müdigkeit um?
- Haben sie konkrete Strategien, die Sie nutzen um mit Ihrer Müdigkeit zurecht zu kommen:
    - Gibt es Strategien, die sich für Sie besonders wirkungsvoll erwiesen haben?
        - Was kann der Grund dafür gewesen sein?
    - 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?
- Wie gehen Sie mit Gefühlen um, die mit Ihrer Müdigkeit einhergehen?
- Denken Sie, dass Sie eine gewisse Kontrolle über Ihre Müdigkeit ausüben können?
    - Wenn ja, wie?
    - Wenn nein, was sind die Gründe dafür?
- Glauben Sie, dass es jemals eine Behandlungsmethoden für (oder ein Medikament gegen) Ihre Müdigkeit geben wird?

- ○ Wenn ja, was denken Sie, kann getan werden?

''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...''

...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?
  - **Hilfe:** *Ich habe es ja grade über einen Zusammenhang gehabt zwischen wie man damit umgeht, wie man darüber denkt und wie müde man ist. Würde Ihnen ein anderer Zusammenhang darüber einfallen, wie müde Sie sind?*

'*'Vielen Dank. Wir sind nun fast am Ende angelangt. Es folgen noch ein paar Fragen zu der Kommunikation über Ihre Müdigkeit.''*

7. Kommunikation

- Ist Ihre Müdigkeit ein Thema während Ihrer Arzttermine oder während anderen Gesprächen mit Fachpersonal?
  - Wenn Ja:
    - Wer spricht das Thema Müdigkeit an?
    - Wie wird das Thema Müdigkeit angesprochen?
  - Wenn Nein
    - Was denken Sie könnten die Gründe dafür sein?
- Fühlen Sie sich in der Lage über Ihre Müdigkeit zu sprechen?
  - Sind Sie mit der aktuellen Kommunikation über Ihre Müdigkeit mit dem Arzt und/oder Fachpersonal zufrieden?
  - Sprechen Sie mit Freuden, Familie oder Bekannten über ihre Müdigkeit?
    - Wenn Ja:
      - Wer sind da ihre nächsten Ansprechpartner?
      - Sprechen Sie oder diese Ansprechpartner das Thema Müdigkeit an?

        - Wie sprechen Sie mit ihnen über Ihre Müdigkeit?
    - Wenn nein:
        - Was sind Ihrer Meinung nach die Gründe dafür, dass die Müdigkeit nicht zur Sprache kommt?
- Sind Sie mit der aktuellen Kommunikation über Ihre Müdigkeit mit Ihren Bezugspersonen zufrieden?
    - Wenn Ja:
        - *Was macht ein für sie befriedigendes Gespräch über ihre Müdigkeit aus?*
    - Wenn nein:
        - Was müsste sich in der Kommunikation verändern?
        - Wie würde die ideale Kommunikation über Ihre Müdigkeit demnach für Sie aussehen?

''Vielen Dank. Abschließend möchte ich Sie fragen:''

8. Zusätzliche

- Gibt es noch etwas, das Sie gerne mit mir besprechen möchten in Bezug auf Ihre Müdigkeit? Oder gibt es etwas von dem Sie denken, es wäre für mich hilfreich zu wissen?
- Haben Sie noch Fragen oder weitere Anmerkungen?

''Wir sind am Ende unseres Interviews angekommen. Ich möchte mich herzlich bei Ihnen für Ihre Offenheit und Zeit bedanken. Falls Sie später noch Fragen oder Anmerkungen haben sollten können Sie sich jeder Zeit an mich wenden. Meine Kontaktdaten haben Sie ja noch? Über allgemeine Ergebnisse werde ich sie, auf Wunsch, nach Ablauf der Studie informieren. Einen schönen Tag noch.''

- Wenn Informationen über Resultate gewünscht*: Wie soll ich Ihnen diese übermitteln?*

Appendix IV – Coding scheme

Codes	Competence	Autonomy	Relatedness
+	Fatigue's origin	Striving for independence	Positive relations
	Being confident	Task-related coping	Communication about fatigue
		Acceptance	People with the same disease
-	Disadvantage towards others	Overwhelmed by fatigue	Retreating
	Torpidity	Limitation	Not bothering others