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Experience Of Fatigue In Rheumatoid Arthritis: A Qualitative Study

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First Tutor: Dr. C. Bode

Second Tutor: Dr. E. Taal

Department: PGT

Author: Anna Dermer

Student number: s1296108

Email: a.dermer@student.utwente.nl

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Abstract

Introduction: Fatigue is a symptom often experienced in rheumatoid arthritis. Cross-cultural studies from the US, UK and the Netherlands investigated the subjective experiences of fatigue in patients with rheumatoid arthritis and found notable similarities in the characteristics and consequences of fatigue among the different populations. Differences were found in the manners of self-management and communication about fatigue. In spite of these studies, little is known about the experience of fatigue in other countries. Therefore, the aim of this study is to gain further insight in the experience of fatigue by focusing on the characteristics, consequences, self-management strategies and ways of communication with health professionals and relatives in a German population.

Method: Sixteen patients with rheumatoid arthritis, gathered via the Rheuma Liga in Gronau, Germany, were individually interviewed. All levels of fatigue were included in this study and explored with the BRAF – MDQ. Semi-structured interviews on the patient's experience of fatigue were conducted and the responses were analyzed using a combined inductive and deductive approach, where in the answers of the patients were summarized and categorized via a coding scheme.

Results: Fatigue is experienced multidimensionally, is unpredictable, and manifests in both a physical and mental state. Consequences have far reaching effects on different aspects of the individual's life, including their choices of activities, spontaneity in life, roles, social interactions and emotions. Patients use different self-managing strategies simultaneously and with differing levels success. Most of the patients did not discuss their fatigue with health professionals or relatives. But when they did, they felt it was dismissed.

Discussion: Results show that there are similarities in the experience of fatigue in rheumatoid arthritis with previous studies from the US, UK and the Netherlands. The differences discovered in the patient's manner of self-management and communication suggest that differences in health systems in the countries have influence on the experience of fatigue. It shows the need for an increased support in a patient's self-management and a well-developed clinical information system that provides enough information to the patient through well-trained health professionals. These results will help practitioners design tailored interventions and self-management guidance.

Samenvatting

Introductie: Cross-culturele studies hebben de ervaring van vermoeidheid bij patiënten met reumatoïde artritis (RA) onderzocht en vonden opvallende overeenkomsten in de kenmerken en gevolgen van vermoeidheid tussen de verschillende populaties. Verschillen worden gevonden in zelfmanagement en communicatie met verpleegkundigen. Over de ervaring van vermoeidheid in andere landen is weinig bekend. Daarom is het doel van deze studie meer inzicht te verkrijgen in de ervaring van vermoeidheid bij patiënten met RA in een Duitse populatie. Met nadruk op de kenmerken, gevolgen, zelfmanagement en communicatie.

Methode: Zestien patiënten met RA, verzameld via de Rheuma Lige in Gronau, Duitsland werden individueel geïnterviewd. Het niveau van vermoeidheid wordt onderzocht met de BRAF – MDQ en alle niveaus worden opgenomen in dit onderzoek. Er worden semi-structureerde interviews gebruikt en geanalyseerd met behulp van een gecombineerde inductieve en deductieve benadering, waarin de antwoorden van de patiënten samengevat en gecategoriseerd worden met een coding-schema.

Resultaten: Vermoeidheid wordt ervaren als multidimensionaal, onvoorspelbaar en komt in een fysieke en mentale toestand. Gevolgen hebben verstrekende consequenties voor verschillende aspecten in het leven van de patiënten: Hun keuzes van activiteiten, hun spontaniteit in het leven, sociale en familie rollen, sociale interacties en emoties zijn beperkt. Patiënten gebruiken verschillende zelfmanagement strategieën tegelijkertijd en met verschillende succes. De meeste patiënten bespreken hun vermoeidheid niet met verpleegkundigen, familie en vrienden, maar als ze het deden werd het geïgnoreerd en afgewezen

Discussie: De resultaten laten zien dat er overeenkomsten zijn in de ervaring van vermoeidheid bij RA met eerdere studies uit de VS, VK en Nederland. Gevonden verschillen in zelfmanagement en communicatie suggereren dat verschillen in de gezondheidszorg in de landen invloed hebben op de ervaring van vermoeidheid. Het toont de noodzaak van een verhoogde ondersteuning bij de zelfmanagement van patiënten en een efficiënt klinische informatie systeem dat voldoende informatie aan de patiënten verstrekt door middel van goed opgeleide verpleegkundige. Dit studieresultaten kunnen helpen om gesneden interventies en zelfmanagement begeleiding te ontwikkelen.

1. Introduction

All around the world, many people are suffering from chronic diseases, including rheumatism, which is often used as a general term for diseases affecting the joint, bones and sinews. One of the most common forms of rheumatism is arthritis. It is one of the most frequent, long-term conditions that affects millions of people worldwide (Barlow, 2009). A special occurrence of this chronic disease comes in the form of rheumatoid arthritis (RA).

The worldwide prevalence is estimated to affect 0.5 - 1 % of the adult population in western countries, whereas two thirds of these patients are female and its prevalence rises with age (Repping-Wuts, 2007; Scott, Wolfe & Huizinga, 2010; Jackel, Gerdes, Cziske & Jacobi, 1993). RA is a systematic, chronic inflammatory disease and is characterized by abnormal reactions of the immune system (van Eijk, 2014; Benhamou, 2006). This means that the immune system works against the own body (Tong, Jones, Craig & Singh-Grewal, 2012). In this process, inflammatory cells invade the synovium, a local area that surrounds the joints and bones, causing hyperplasia, a rapid increase in cell production, and formation of pannus tissue. This irruption consequently damages the cartilage, causes erosion of the bordering bones and results to the loss of function in the concerned joints (Scherer, 2013). This inflammatory reaction can also affect other organs and can have a negative impact on their long-term function (Bode & Taal, 2015; Scherer, 2013). Followed by worse physical and psychosocial symptoms such as pain, physical limitations and functional loss, joint destruction, deformity, tender and swollen joints, stiffness, sleep disruption, depressed mood, anxiety, fatigue, which overall causes a huge disability in daily life (Barlow, 2009; Barlow, 2006; Nikolaus, 2012; Treharbe, Lyons, Hale Goodchild, Booth & Kitas, 2008; Van Eijk, 2014). Furthermore, patients report changes in work capabilities, income, rest during daytime, leisure time activity, transport mobility, housing and social support (Albers, Kuper, Van Riel, Prevoo, Van 'T Hof, Van Gestel & Severens, 1999). Albers et.al. (1999) discovered that work disability appears to be four to fifteen times higher than in the compared general population. After three years of suffering from RA, 42% of the patients were registered as work-disabled, a quarter of the respondents experienced income reduction, 40% reported that they need extra rest during daytime and 52% reported a decline in transport mobility. In another study, it was found that patients who suffer from RA had fewer non-paid jobs,

performed fewer household activities and that their disease had negative influence on their social participation (Van Jaatsveld, Jacobson, Schrijvers, Van Albada-Kuipers, Hofman & Bijlsma, 1998). Thus, RA has far reaching consequences in the general livelihood and well being of the patients in general.

Therefore, it is absolutely vital that the treatment and care addresses the multidimensionality of complications associated with such chronic diseases such as RA. For instance, the Chronic Care Model (see Figure 1) describes a framework for an ideal chronic illness care (Van Eijk-Hustings, Kroese, Bessems-Beks, Landewé & Vrijhoef, 2012). According to Van Eijk-Hustings et. al. (2012), the model claims that a combination of effective interventions focused on the level of community services, health care services, health care professionals and patients result in functional and clinical outcomes of care. The community increases the outcome of health care through resources and politics, as for example by obligating one to be a member of a health insurance company. This accordingly regulates the healthcare system. Within the health care system, the relationship between management strategies and patients values and choices can be improved if there is an active role in the patient's decision-making process and increased support in the patient's self-management. Also, a proactive and focused health care system that focuses on the overall welfare of the individual improves the support of self-management and patients decision-making process. To improve the quality of treatment for chronic illness, it is vital to have a well-developed clinical information system that provides enough information to the patients and the health professionals. This will support the everyday activity of the patients and create the possibility for a productive interaction between a team of well-trained and productive health care professionals and informed and activated patients. In this sense, administering special trainings in order to have professionally educated health care professionals can be advantageous. Good communication between the professionals and the patients plays a crucial role in improving the results of health care. This can be achieved through special interventions provided by the health care system or the community. One example of this would be by enclosing special guidelines about communication within the established practice protocol or by improving coordination within the practice team which increases the time available for patients.

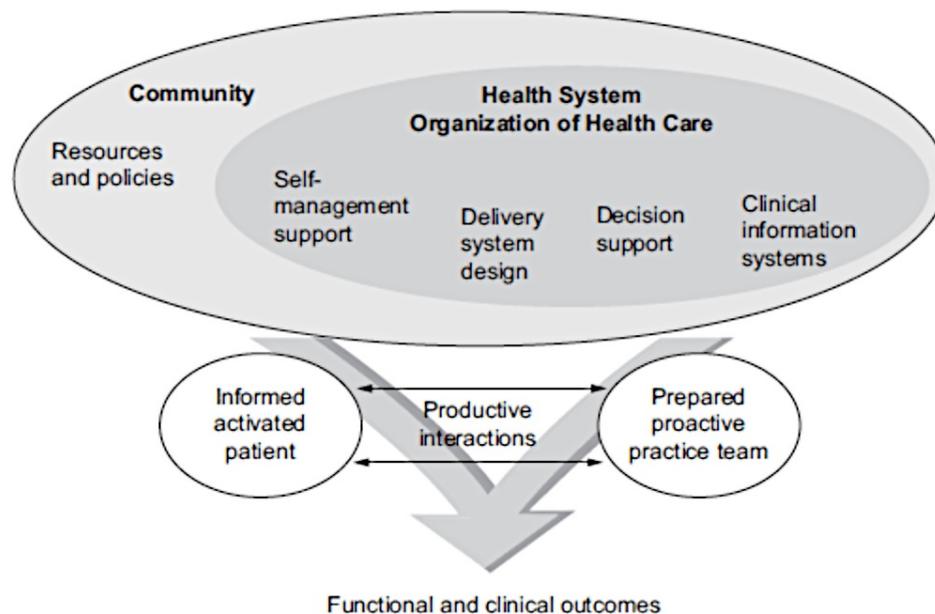


Figure1. *Chronic Care Model (de Luisgnan, 2014)*

However, in many European countries such as the Netherlands and Germany, the framework of the Chronic Care Model is either at an early stage of development or is not yet implemented at all.

The current treatment and care of RA in the most European countries focuses primarily on medication to restore the disfunction of the immune system (Van Eijk, 2014), including Disease Modifying Anti Rheumatic Drugs (DMARDs) and biological medications that seem effective in early stages of the disease, resulting in a decrease of disease activity (Boers et. al., 1997; Furst et. al., 2005; Van Eijk, 2014). But medication alone is not sufficient in resolving the negative impact of RA on the patients daily life. In response, a number of countries implemented a multidisciplinary approach that is different from the traditional one, where only rheumatologists are responsible for the management of disease treatment (Van Eijk, 2014). In a multidisciplinary approach, other health care professionals apart from the rheumatologist are included in the treatment and care of patients with RA such as a physiotherapist and clinical nurse specialist (Van Eijk, 2014). Clinical nurse specialists are nurses that are specialized in the care of patients with a specific chronic disease (Ttjhuis, Zwinderman, Hazel, van de Hout, Breedveld & Vlieland, 2002), which in this case is in the field of rheumatoid arthritis. They act as an interface between the patients and other health

care professionals in the multidisciplinary team and support patients in disease related problems (Van Eijk, 2014; Van Eijk et. al., 2012). By doing so, they are involved in monitoring disease activity, medicine treatment and side effects, managing exacerbations (Van Eijk, 2014 cited by Hill, Bird, Harmer, Wright & Lawton, 1994; Hill, Thorpe & Bird, 2003), self management support, patient education and counselling, and intra articular injections (Van Eijk-Hustings et. al., 2012).

However, there seem to be differences between European countries with regard to clinical nurse specialists, because not all employ clinical nurse specialists within rheumatology. In some of the countries, rheumatology-nursing specialists do not exist, therefore, the care given by nurses is not equally available for all patients with RA (Van Eijk-Hustings et. al., 2012; Van Eijk, 2014). A study by Carney (2015) summarized a list of European countries that have and have not implemented clinical nurse specialists in rheumatology. He discovered that the profession of special nurses exists in the Netherlands but is still in early stage of development. Nevertheless, the positive effects of that change in the health system in the Netherlands are still measurable. Tjhuis et. al. (2002) conducted a survey which revealed that patients with RA in the Netherlands who had access to a rheumatology nurse specialist acquired more knowledge and also were more satisfied with their care and treatment. However, such positive developments cannot be said for other European countries, namely Germany (Carney, 2015). There is no clinical nurse specialist in the German rheumatology setting, even though some research studies show that patients have the need for such clinical nurse specialists (Carney, 2015). Mühlhauser, Meyer and Steckelberg (2010) talk about an increasing number of patients who want to understand clinical research findings of new therapies and medicines. This plays an important role in the patients decision making process in RA. However, a great number of physicians think that sharing information with patients is too time consuming. Hence a new structure in information provision is needed, where a clinical nurse specialist could play a central role. In Germany, more research is needed to understand the whole situation for patients with RA because of the contrasting development in the health systems among countries.

1. 1. Fatigue in rheumatoid arthritis

As mentioned above, RA is accompanied by a many distressing and disrupting symptoms. One of these symptoms is fatigue. In healthy people, fatigue is a normal and temporary phenomenon (Benhamou, 2006). It is a state that follows a period of mental or physical activity, characterized by a lessened capacity for work and reduced efficiency of accomplishment, usually accompanied by a feeling of weariness, sleepiness or irritability and may be relieved by rest (Swain, 2000). Little is known about this phenomenon and if it continues to remain unresolved, it can become a chronic state as it is the case in the most chronic diseases, including RA (Repping-Wuts, Fransen, van Achterberg, Bleijenberg, G. & Van Riel, 2007). A concrete theoretical model that explicitly explains the experience of fatigue in RA is not yet in existence (Nikolaus, Bode, Taal & Van de Laar, 2010b). However Hewlett et. al. (2011) proposed a conceptual model (see Figure 2) reflecting interactions between three dimensions: RA dimension (disease process), cognitive and behavioural dimension (thoughts, feelings and behaviour) and personal dimension (personal issues in the life of the patients).

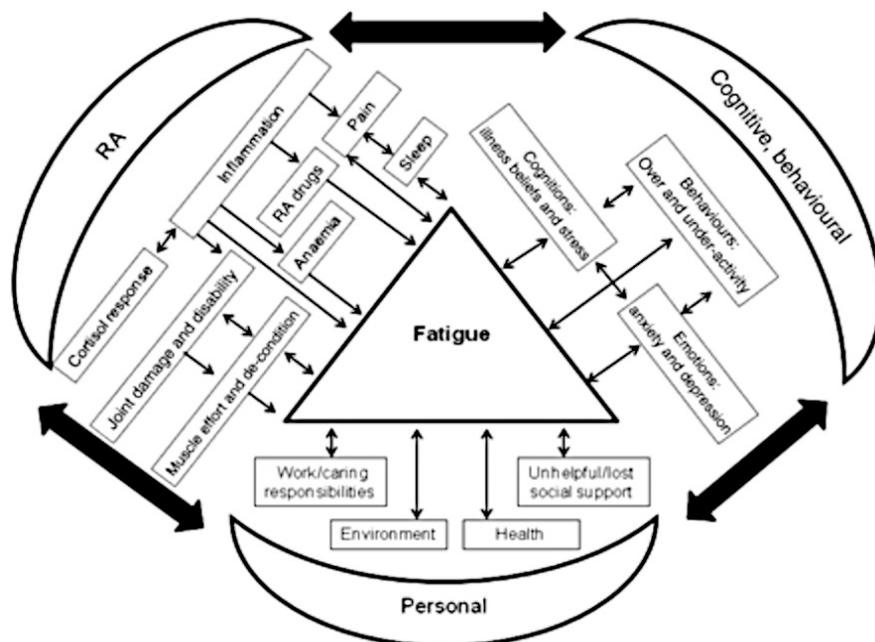


Figure 2. Conceptual Model of Fatigue in Rheumatoid Arthritis (Hewlett et. al. 2011)

Bear in mind that this model is still a conceptual picture and more insight should still be

obtained in the complexity of fatigue (Nikolaus, Bode, Taal & Van de Laar, 2010b). Furthermore, fatigue is a common complaint among patients with chronic diseases including RA and it exists in all gradations of the disease (Benhamou, 2006; Van Riel & Repping-Wuts, 2009). It is present in 88-98% of patients with RA and a great number of patients report fatigue to be a problematic, challenging and aggravating aspect of their illness besides pain (Wolfe, Hawley & Wilson, 1996; Swain, 2000; Van Riel & Repping-Wuts, 2009). To understand the impact of this phenomenon on the life of patients it will be explained in more detail in the following passages.

Fatigue in chronic diseases is a systematic feeling of exhausting (Treharbe, Lyons, Hale, Goodchild, Booth & Kitas, 2008). It seems to be long lasting (Benhamou, 2006), poorly relieved by rest, not related to exertion (Swain, 2000) and extreme and unresolved (Hewlett, Cockshott, Byron, Kitchen, Tipler, Pope & Hehir, 2005). In general, fatigue in RA is known as a subjective, multicausal and multidimensional symptom (Stufbergen & Rogers, 1997; Magnusson, Moeller, Ekman & Wallgren, 2001) including pain, disability, inflammation, sleep disturbance and psychosocial factors (Repping-Wuts, Uitterhoeve, Van Riel & Van Achterberg, 2007). Also fatigue seems to be associated with anxiety, disability, less social support and more social stress (Mancuso, Rincon, Sayles & Paget, 2006). Because of its subjective nature, fatigue should be assessed according to how a patient describes it (Nikolaus, Bode, Taal & Van de Laar, 2010). It therefore becomes problematic to characterize and define fatigue in a general manner (Swain, 2000). In literature, no consensual definition of fatigue exists (Piper, 1993). However, most authors define fatigue as: "An overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work" (Van Riel & Repping-Wuts, 2009, p. 996). Another popular definition that is frequently used in research is one given by Piper (1993):

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 a profound negative impact on the person's quality of life (p. 286).

Behamou (2006) gives another definition of fatigue: "Fatigue is a enduring subjective

sensation of weakness, lack of energy, generalized tiredness or exhaustion. Subjective thereby implies that fatigue is a self recognized phenomenon imbedded in the individual's own evaluation of the current personal state" (pp. 385-386). Patients describe fatigue often as an unpredictable, overwhelming symptom that is different from normal tiredness because it is extreme, often not earned, unpredictable, unresolved and has a great impact in daily life, even greater than the effects of pain (Van Riel & Repping-Wuts, 2009). They report that fatigue has physical, cognitive and emotional components and is attributed to increased inflammation, increased functional loss of the joints and disturbed sleep (Hewlett et. al., 2005; Crosby, 1991). The capacity to carry out daily tasks and responsibilities are affected by fatigue in RA, as well as common family and social roles (Flensner & Söderhamn, 2003). A great amount of patients do not discuss their fatigue with healthcare professionals, because they feel that it is often dismissed (Hewlett, Cockshott, Byron, Kitchen, Tipler, Pope & Hehir, 2005; Swain, 2000), underestimated (Flensner & Söderhamn, 2002) or they simply choose to manage it alone (Van Riel & Repping-Wuts, 2009). The definition is not the most important issue in clinical practice, but rather the way patients experience fatigue because of their disease and how it can and should be further explored.

In response to this dilemma, a handful of qualitative investigations regarding the experience of fatigue in patients with RA were conducted in the USA, the UK and the Netherlands. The main results show that patients experience fatigue multidimensionally, intensely and inconsistently, striking every sphere of life and has far reaching consequences such as social limitations, affected self-esteem and affected quality of life (Tack, 1990; Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, van Riel & Achterberg, 2007; Nikolaus, Bode, Taal & Van de Laar, 2010a). Patients notice that fatigue influences their fulfilment of social roles, self-management is variable and professional support is rare (Hewlett et. al., 2005; Repping-Wuts, Van Riel & Achterberg, 2007). Nikolaus, Bode, Taal and Van de Laar (2010a) conducted one of the named qualitative studies on fatigue in the Netherlands among a Dutch population. They found similar results and additionally gained new insights in the role of benefit finding, among patients with RA with experience fatigue. They discovered that patients with RA who have experienced fatigue report that they perceive more social support from relatives, health professionals and strangers. This dimension of fatigue was not found in

the other studies. The area that other studies failed to address could be the role of benefit finding with regard to the patients RA related fatigue.

Other differences among the studies are present in the perception of self-management and the communication with health professionals. Hewlett et. al. (2005) report that patients in the UK think they have to manage their fatigue alone and that nothing can be done either by themselves or their doctors. This belief reflects a hesitation in accepting support from health professionals or others. These requests have been dismissed in the past (Hewlett et. al., 2005). Repping-Wutts, van Riel and Achterberg (2007) have similar results. Dutch patients also perceive that they struggle alone to manage their fatigue. They seldom report fatigue to health professionals because they think it cannot be treated and that they have to manage it alone, like patients from UK. A main difference between them is, that patients in the Netherlands use positive coping strategies as downward comparison and acceptance as the patients in the US do (Tack, 1990). Comparatively, the US population use friends and family to help manage their fatigue and to share their problems with health professionals and others (Tack, 1990). A reason for these differences could be the difference in national health care systems among countries, and so the care and treatment of patients with RA also differs. In summary, the results overlap largely, with the exception of the communication between patients and health professionals respectively related others and patients self-management. These two aspects seem to be different in some way according to the cross-cultural studies, which explored the experiences of fatigue in patients with RA. However, it is not known yet how fatigue is experienced in other countries besides the US, the UK and the Netherlands. This seems to be an important domain of research to find out more about the potential similarities or differences in different countries with regard to patient experienced fatigue. To investigate if the results from the previous studies in the US, the UK and the Netherlands will be confirmed for a German population and to add new insights about the experience of fatigue in RA, further research is needed.

With that said, the aim of this study, is to explore how fatigue is experienced in patients with RA in a German population, from the patients point of view, to contribute to a better understanding of the phenomenon. Furthermore, the results will be analysed in relation to cross cultural information from other studies conducted in the USA, the UK and

particularly the Netherlands to examine cultural similarities and differences in the experience of fatigue in patients with RA. The German population is chosen because there any research about the experience of fatigue in patients with RA is not available at the moment. To implement this study, a qualitative research design is chosen because qualitative methods are the most appropriate way of ascertaining the experience of subjective symptoms such as fatigue in RA. This method is also particularly useful in identifying how patients manage fatigue because the data is grounded on the patient's language and experiences (Benhamou, 2006).

A semi-structured interview will be conducted, focusing on four relevant dimensions: experiences of fatigue (dimensions), self-management of fatigue (strategies), consequences of fatigue (impact on daily life) and the communication in relation to fatigue (with health professionals and relatives). These aspects are repeatedly mentioned in the cross-cultural literature about experiences of fatigue in patients with RA (Tack, 1990; Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007; Nikolaus, Bode, Taal & Van de Laar, 2010a). Because of the qualitative research design, no concrete hypothesis will be formulated, but based on the mentioned studies above it is expected that the results will show similarities in the experiences and in the consequences they mention. A difference is expected in communication and self-management, because of the findings of the previous mentioned studies that found that there are differences in communication and self-magement and the differences in the health systems, particularly in Germany and the Netherlands. This study will be guided by the following questions:

1. How do patients with rheumatoid arthritis report their subjective experience of fatigue?
2. How do they experience the consequences of their rheumatoid arthritis related fatigue?
3. How do they self manage with their rheumatoid arthritis related fatigue?
4. How do they communicate with health professionals and relatives about their rheumatoid arthritis related fatigue?

2. Methods

2. 1. Procedure

Through the Rheuma Liga in Gronau, Germany and through personal contacts from the research team, thirty-one patients with rheumatoid arthritis were invited to participate in this study about the experience of fatigue in rheumatoid arthritis. The research team consists of two researchers that are students from the faculty of behavioural sciences at the University of Twente, The Netherlands. The patients were either contacted by post, e-mail and/or telephone. The patients who were contacted via post also received a short information flyer with the purpose and the subject of the study. Additionally, the patients were informed about the duration of the interview and the same time notified that their data would be handled anonymously. Contact information from the research team was also mentioned on the information flyer. The original version of the flyer is given in appendix I. The selection criteria for participation in this study are as follows: the ability to speak, read and understand the German language, a diagnosis of rheumatoid arthritis and the experience of fatigue. This is because the experiences from individuals that have no rheumatoid arthritis related fatigue might be different than from patients that have them. There are also two excluding criteria: severe comorbidities as a diagnosed depression or another severe medical condition and if the patient has completely solved his fatigue (through special treatments such as a sleeping mask). This was controlled through personal reports from the patients, which was taken in advance and during the interview itself. Interested patients that meet the above mentioned criteria were asked to make an appointment by telephone or e-mail. In most cases, one of the two interviewers (researchers) went to the home of the patient. The facilities of the Rheuma Liga in Gronau, Germany were also a location for conducting interviews.

A quantitative pen and paper questionnaire was used to describe the study population in more detail with regard to the severity of their fatigue symptom and their experience and impact of rheumatoid arthritis related fatigue. Patients completed the free to use German version of the Bristol Rheumatoid Arthritis Fatigue Multidimensional Questionnaire (BRAFF – MDQ). The questionnaire consists out of 20 items and measures a total fatigue score (severity) and different domains of fatigue: physical fatigue (e.g. How you lacked physical energy because of fatigue?), living with fatigue (e. g. Has fatigue affected your social life?),

cognitive fatigue (e. g. Has fatigue made it difficult to think clearly?) and emotional fatigue (e. g. Has being fatigued upset you?) (Nicklin, Cramp, Kirwan Jr, Urban & Hewlett, 2009). The psychometric quality of the BRAF – MDQ is good, with an internal consistency for total fatigue from 0.93 (physical fatigue 0.71, living with fatigue 0.91, cognitive fatigue 0.92 and emotional fatigue 0.89) and a test – retest reliability for total fatigue from $r = 0.95$ (physical fatigue $r = 0.94$, living with fatigue $r = 0.89$, cognitive fatigue $r = 0.89$ and emotional fatigue $r = 0.92$) (Hewlett, Dures & Almeida, 2011). There are four response options ranging from "not at all" to "very much" (Nicklin, Cramp, Kirwan Jr, Urban & Hewlett, 2009). Through summation, a total fatigue score can be calculated, it ranges from 0 – 70 and the scores for the dimensions ranges for physical fatigue from 0 – 22, for living with fatigue from 0 – 21, for cognitive fatigue from 0 – 15 and for emotional fatigue from 0 – 12, and could also be calculated through summation (Nicklin, Cramp, Kirwan Jr, Urban & Hewlett, 2009). Therefore a higher score reflects high severity of fatigue.

A low fatigue score was no exclusion criterion, because previous studies in the US, the UK and the Netherlands show that patients with different fatigue scores share a lot of similarities in their answers regardless of the severity of fatigue and just slight differences in their self-management strategies and the interaction with health care professionals (Tack, 1990; Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007; Nikolaus, Bode, Taal & Van de Laar, 2010a). The mentioned studies used different scores of fatigue as inclusion criteria, but the answers of the patients did not differ significantly. The reasons therefore could be the difference in interview questions or other external circumstances as the different health care systems within the respective countries, that either provide supportive self-management and active interaction between patients and health care professional or not. Thus, meaning of fatigue remains the same even with different scores in severity of fatigue.

Furthermore, the patients were personally interviewed by one of the researchers in a semistructured format and were recorded on to audiotape, lasting around 30 – 90 minutes. The participants were divided into two groups, where in one group was assigned to one of the two researchers for interview. An informed consent was used to guarantee that the patient's participated consciously and that they provided all relevant and true information for

the success of this study. The patients were informed that the audiotapes will be destroyed after the analysis and that all data will be handled anonymously. The original version of the informed consent can be found in appendix II. Detailed information about the interview will follow.

The study proposal was presented to the ethical committee of the behavioural science faculty of the University of Twente, Enschede, the Netherlands. The committee concluded that the proposal and the design of this study is ethically justifiable because filling-out a questionnaire and being interviewed on fatigue in rheumatoid arthritis is not burdensome for the patients.

2. 2. Sample

The sample consisted of 16 patients who meet the requirements of this study and have been diagnosed with rheumatoid arthritis who above all agreed to participate in this study. One man (6,25 %) and 15 (93, 75 %) women completed the questionnaire and participated in the interview. There was one female participant dropout because she complies with an excluding criterion. She reported that she has completely solved her fatigue with a special treatment, namely with a medical sleeping mask (participant 14, women, 64). The remaining 15 participants range from 22 years to 79 years, with a mean age of 56.13 years (SD = 15.76). The duration of rheumatoid arthritis in this sample ranged greatly from 1 year to 43 years, with a mean of 18.4 years (SD = 11.77). Some additional characteristics of the sample are: most patients lived in an at least a two-person household (N = 14), two patients lived alone. Ten patients graduated from secondary school (N = 10), three have a university degree and the rest (N = 3) mentioned other levels of educational attainment (N = 3). Four of the patients engaged in normal paid work, mostly half time. One of them is currently looking for a new job. Two of the patients were students of more than 3 years and one patient was a homemaker. Four patients receive pension and five receive invalidity pension. Eight patients are married, whereas two are widowed, two were divorced. Four were single. Some of the patients did not use medicine for their rheumatoid arthritis (N = 2) and also did not visit a rheumatologist (N = 3). While a lot of the patients use other treatments (N = 13), as pain therapy (N = 2), homeopathy (N = 3), acupuncture (N = 3), meditation (N = 1) and different

exercises (N = 8) as physiotherapy and water-gymnastic. Eleven of the patients have sleeping difficulties and low comorbidities. These were high blood pressure (N = 2), diabetes (N = 2), osteoporosis (N = 1), asthma (N = 1) and not further defined psychological problems (N = 1). An overview of the characteristics of the sample is given in table 1.

Further in this sample, the total mean BRAF - MDQ score for the fatigue severity in the last seven days before the interview was 26.81 (SD = 14.83). The mean sub-scores for the different dimensions of the BRAF - MDQ were 11.50 (SD = 4.40) for the physical fatigue dimension; 6.69 (SD = 5.86) for the living with fatigue dimension; 5.31 (SD = 3.90) for the cognitive fatigue dimension and 3.31 (SD = 3.14) for the emotional fatigue dimension. The mean scores show that this sample has in total a relatively low fatigue score and low scores on the dimensions in comparison to other studies. In other words, the total fatigue severity in this sample is relatively low, with low physical impact on the patient because of their RA fatigue, low impact on the lives of the patients, low impact on the cognitive abilities of the patients and also low emotional reactions or emotional impact because of patients' RA fatigue. Nonetheless, it is notable that the standard deviations of the mean total score and the scores of the dimensions are quite high. This signifies low reliability for the found scores on the BRAF - MDQ. It seems that some patients scored very high or low on the BRAF - MDQ and therefore increase or decrease the overall mean score of the total fatigue score and the scores on the dimensions of fatigue.

Nevertheless, these BRAF - MDQ scores have little meaning for the qualitative information of the patients. Other studies that investigated the experiences of fatigue in patients with rheumatoid arthritis showed that the qualitative measured fatigue score had no or little influence on the answers that patients gave. Most of them used different measurement instruments, with different cut-off scores as inclusion criteria for their study. Still, they found huge similarities in the answers patients gave. Some used a visual analogue scale (VAS) to measure the severity of fatigue. Hewlett et al. (2005) used a 10 cm VAS with a relatively high cut-off score of ≥ 7 whereas Nikolaus, Bode, Taal and van de Laar (2010a) used a VAS ranging from 0 to 100. The cut-off score is not mentioned in the published article. On the other hand Repping-Wutts, Uitterhoeve, van Riel and Achterberg (2007) used the Checklist Individual Strength (CIS) to measure fatigue, ranging from 0 to 56. Although the

measurement instruments were different or had different rangings the found results overlap considerable, concluding that the low fatigue score in this sample measured by the BRAF – MDQ should not influence the answers of the patients in a great sense.

Table 1. *Demographic data and characteristics*

Characteristic	Mean	Standard Deviation	N
Age	56.13	15.76	16
Duration of Illness	18.40	11.77	16
Sex			
Female			15
Male			1
Education			
Secondary school			10
University degree			3
Other graduation			3
Work Situation			
Working			3
Seeking work			1
Homemaker			1
Student			2
Pension			4
Invalidity Pension			5
Marital Status			
Single			4
Married			8
Widowed			2
Divorced			2
Living alone			2
Comorbidities			
High blood pressure			2
Diabetes			2
Asthma			1
Osteoporosis			1
Psychological diseases			1
Sleeping difficulties			11
Use regularly medicine			14
Go regularly to a rheumatologist			13
Other treatment			
Exercise			8
Pain therapy			2
Homeopathy			3
Acupuncture			3

2. 3. Interview

The interviewers used a hierarchical interview scheme, which covered seven main topics (table 2) including several subquestions. The interview scheme is based on the interview guideline used in previous interview studies about fatigue in rheumatoid arthritis (Repping-Wuts, Uitterhoeve, Van Riel, Van Achterberg, 2007; Nikolaus, Bode, Taal, Van de Laar, 2010; Hewlett, Cockshott, Byron, Kitchen, Tipler, Pope, Hehir, 2005). The main topics include 1) general demographic informations about the patients, as for example the age, duration of their RA and their marital status; 2) experience of fatigue and whether the patients differentiate their fatigue from normal fatigue; 3) the subjective causes of their fatigue; 4) consequences which the patients experience because of their fatigue; 5) the time line of their fatigue; 6) how the patients cope with their fatigue; and 7) their experience of communication about their fatigue with health professionals and their relatives. An opportunity for additional comments and unresolved questions from the patient's side of view is inquired in the end of the interview scheme.

In order to assure a standardized interview scheme, each patient received the same information previous provided by the interviewer and was asked the same main questions and subquestions. Although, the order of the questions could be changed and adapted according to the patient's response and on the judgement of the interviewer. If the patient had some difficulties in understanding a question, the researcher was allowed to paraphrase the question without straying away from the original. Also, if it became necessary to get more detailed informations, the interviewer could ask the patient follow-up questions that were not explicitly mentioned in the interview scheme.

The interview scheme was piloted in one interview by one of the researchers and afterwards transcribed verbatim. After discussions and the reaching of a consensus the research team made minor amendments. The pilot interview was included in the final analysis. The two researchers remain in contact with the patients in duration of the interviews. If in case after an interview new questions arise that could be important in answering the research questions, the interviewer discussed them and after consensus included or excluded them from the scheme. After the pilot interview, no new questions arose. The comprehensive interview scheme can be found in appendix III.

Table 2: *Interview Topics*

Topic	Example Question
Demographic - and disease related informations	How long have you been suffering from your disease?
Experience of fatigue	How would you describe your experiences with fatigue?
Causes of fatigue	What causes your fatigue?
Consequences of fatigue	How does fatigue affect your daily life?
Time line of fatigue	Would you describe your fatigue as acute, episodic or chronic?
Coping with fatigue	Do you have concrete strategies to cope with your fatigue?
Communication about fatigue	Is your fatigue an issue brought up during your medical appointments?

2. 4. Analysis

All semi-structured interviews were recorded on audiotape and transcribed verbatim. The transcripts were subjected to analysis using the software program Atlas.ti. This program helps to systematically analyse complex phenomena hidden in unstructured data, as interviews. The program provides tools that let the user locate, code and annotate findings in the data to weight and evaluate their importance and to visualize the relations between them. The program allows marking for later editing and notes can be written during the coding session. All data are stored on the computer hard disk. The configuration of Atlas.ti allows for the development of categories, called groups. For example the codes "read a book", "listen to music" and "go outside" were summarized to the category "distraction from fatigue". The transcripts were carefully read and reread and all phrases were systematically coded by one researcher by using Atlas.ti. The interview was analysed in an interactive development through combination of an inductive (bottom up) and deductive (top down) approach. The two approaches were combined because there exist theoretical assumptions about the experience of fatigue in RA from previous studies from other European countries, but to guarantee that

all information is provided in importance the analysis was not limited to the theoretical assumptions but the bottom up information was also analysed. In the first step, three random interviews were analysed bottom up, which means that the interviews were coded and summarized without using a predetermined coding scheme. Beginning with one of the three interviews each segment of an interview was analysed and coded. The primary focus lies on the quantity of certain aspects in the story from the patients. If a common and reoccurring aspects emerges, as for example "less time for children", a code was created that describes it in general, as for example "disability to full fill family roles". This process continued throughout the three interviews. To compress the coding scheme codes were summarized and grouped into one code. In the end a coding scheme was created without using predetermined categories.

In the next step, a second coding scheme was developed top down. This coding scheme was not developed by analysing the interviews of this study. It comprised of a combination of the main interview topics from this study (demographic information, experience of fatigue, causes of their fatigue, consequences because of their fatigue, the time line of their fatigue, coping with fatigue and communication about fatigue) and some topics from an already existing coding scheme from another interview study about fatigue in rheumatoid arthritis (Hewlett et. al., 2005). The main interview topics were similar to the coding scheme from the named study by Hewlett et. al. (2005), therefore only a few codes were added to the top down developed coding scheme.

Subsequently, the first coding scheme that was developed bottom up was compared to the top down developed one. The codes that were related, similar or equal were summarized to one code. So that a new coding scheme was developed through a combination of the bottom up coding scheme with the top down coding scheme. A lot of similarities were found between the codes but if new codes emerged they were added to the new scheme. Finally, a coding scheme was developed which combined top down coded categories with the new emerged bottom up found categories from the answers of the patients.

In the next step, the remaining interviews were analysed, based on the developed coding scheme. If still a new code emerges, it was added to the coding scheme (bottom up). After the fifth interview, no new codes appeared, indicating data saturation. All interviews

were coded, and afterwards the codes were grouped into more broad categories by the researcher. Therefore it was important that the codes had similarities or were related. Finally, the broad categories that were related were grouped into overarching themes. A comprehensive coding scheme can be found in appendix IV.

3. Results

Sixty-five codes were initially identified, which were later on grouped into 30 categories and finally into four overarching themes: 1) fatigue was experienced as multidimensional 2) affecting every domain of their live, that 3) self management is flexible, and that 4) communication about fatigue with health professionals and relatives is rare. A link between the first and second category is evident. The characteristics of fatigue caused by rheumatoid arthritis links with the consequences patients reported. The enormous consequences define the experienced characteristics of fatigue somewhat.

3. 1. Characteristics of fatigue – multidimensionality

Patients reported that their rheumatoid arthritis related fatigue is different from former experiences with exhaustion and that fatigue differs from the tiredness that follows after strenuous activities such as sports. The RA fatigue can be characterized through unpredictability, sudden occurrences and the lack of clear explanations as to why their fatigue occurs.

"So a normal fatigue, I'll say, if someone, no idea, has now cleaned the house or windows. Then one is tired but that is different. That announces itself a little. I have done enough now and now I'm tired, right. But this fatigue that comes now is suddenly there and cannot be influenced. (...) It often comes like lightning from a bright blue sky. So really, I'm actually still fine and I suddenly notice that I am becoming so tired. And then I have great difficulty to keep my eyes open" (participant 10, women, 58).

Also, patients reported that their former tiredness and the tiredness resulted from strenuous activities goes away after sleep or rest but that their RA fatigue seems to be a permanent

condition that can not be reduced through rest.

"If I had been exercising, I would probably be tired about half an hour after that. Then I would lie down, but after that I would be fit again (...). But this is a permanent condition. (...) The fatigue from rheumatism is that you are continuously tired, it doesn't go away" (participant 15, women, 50).

"An attendant circumstance fatigue, probably. An accompanying fatigue somehow. Yes, which kind of accompanies you" (participant 7, women, 50).

According to the patients, the experience of fatigue varies in duration, lasting from just minutes or up to the entire day.

"Well an hour, 45 minutes and then everything was okay again" (participant 10, women, 58).

It varies in frequency, from experiencing fatigue daily or as a permanent condition; or being fatigued only in in period when their RA is acute.

"I am only tired once and that is forever" (participant 1, women, 59).

"You get up in the morning and are tired. That doesn't go away for the entire day. You have moments in between in which you are fit as a fiddle and then you have five minutes again in which you could nod off immediately" (participant 15, women, 50).

"Sometimes I have it quite often in a day and sometimes not so often" (participant 8, women, 79).

Fatigue also varies in severity, from being experienced as absolutely worse to being barely felt because it feels very weak or even absent. There are patients who reported that their fatigue is worse than pain. But the same number of patients said the opposite, that their pain

is worse than their fatigue. Half of the patients reported that their fatigue happens episodically whereas the other half reported that their fatigue happens chronically. Furthermore, a lot of the patients could not point out when they recognised their fatigue for the first time. Since there is a great variety in the experienced characteristics of RA fatigue, it is possible, that not only fatigue is reported in the interviews but a combination of more symptoms related to rheumatoid arthritis.

Furthermore, they experienced different forms of fatigue, either a physical or a mental fatigue. The physical fatigue appears often with physical conditions as headaches, heavy and burning eyes and having no or less energy. Further physical fatigue has components as heaviness, feeling drained, weary, overstrained, cut off and be listless.

"So you notice how all your energy closes down, your eyes start to burn, so it really is like this and you can't continue and you don't want to talk to anyone anymore or anything, you're just tired" (participant 10, women, 58).

"Yes. You are simply lethargic. Every task is difficult for you" (participant 3, women, 78).

"You're (...) lethargic, and you also don't want to sleep, you just want to rest. Your body is weary, exhausted" (participant 15, women, 50).

The mental fatigue is characterized by less concentration and the wish to rest or sleep and to be left alone.

"You just want to lie down now and hear nothing and see nothing" (participant 3, women, 78).

The patients distinguished a fatigue with prior reasons. These reasons can be identified as specific triggers of fatigue. Patients reported that they get fatigued if they had done too much, or if they gone to work.

"It depends on the day, what one has done. If I've been in the garden all day I'll probably nod off" (participant 12, women, 54).

Also, performing (hard) tasks seems to be a trigger or reason for getting fatigued. Patients reported, that they feel fatigued after doing household chores such as gardening. In addition the inability to exercise or to move as much as before rheumatoid arthritis is also reported as a cause for fatigue.

"Since you practically don't do anything anymore. I used to be so active, I rode my bicycle, I went running and rollerblading. I'm not allowed to do anything anymore. (...) You're not allowed to be active. (...) You just get lazier. I used to be fitter when I was still exercising a little. I still had 2-3 hours in which I could do things. You get lazier and then you get tired and even more tired" (participant 15, women, 50).

Other triggers mentioned include having emotional stress by thinking too much about personal problems.

"I honestly believe that it has something to do with the psyche. If you don't feel so good and life isn't going how you imagined, then the body reacts. And if you're doing well and have friends and are treated nicely it's better" (participant 4, women, 54).

Further the weather conditions plays a role in getting fatigued according to the patients. Patients reported that the weather influences their mood, as for example influences bad, dark weather the mood negatively what worsens their fatigue.

" (...) Depends on the weather. If the sun is shining you are happy to do things but if it's raining and constantly dull (...) than it's worse" (participant 2, male 75).

"And if the weather isn't quite so nice then one is also a little (...) dreary somehow" (participant 6, women, 61).

Some patients reported that disturbed sleep is a reason or trigger for their fatigue. Patients said that if they did not get enough sleep, they experience fatigue. They also reported that they feel fatigued when they do not get enough sleep because they wake up a lot during the night.

"I believe that if I don't sleep enough the fatigue will come. (...) If I sleep less I notice that I am less, so if you start with a low energy level than you can forget getting up. Then the day is basically fucked up" (participant 16, women, 22).

"Last night it was the last time at two-thirty and at six o' clock I was already awake again and haven't slept since (...) I'm tired" (participant 1, women, 59).

Another trigger that was mentioned was social support. Some patients reported that instead of receiving social support, they are placed under social pressure and therefore get fatigued. They thought that their social surrounding expect that they have to perform on the same level as before their RA

"I think that the fatigue sometimes comes from the mind. (...) If too much assails upon me because I know that I cannot achieve what they expect from me, it makes me depressed and also very tired" (participant 4, women, 53).

Other patients even termed specific causes rather than triggers of their fatigue. Most patients believed that the cause for their fatigue is rheumatoid arthritis and their RA related pain.

"The cause is probably connected to the illness since it is a symptom of it. Since the body needs a lot of energy to react to the illness and that makes you tired" (participant 12, women, 62).

"A lot of pain means a lot of strength. (...) For the body it is a kind of work to cope with it" (participant 4, women, 53).

Interestingly, some patients report that the medicine that they take for their RA is the cause of their fatigue.

"I've always said, since I have rheumatism I have to take pills and they make me tired" (participant 5, women, 59).

But still some patients report that their fatigue is not caused by RA but by other physical conditions such as ageing, malfunction of their thyroid gland and iron deficiency.

"(...) But then I always put it off to not having enough iron in my blood (...). Then I always say: Ah yes, now you have too little iron. Now you should take another iron pill (...) so that you get active again" (participant 4, women, 53).

Finally, it seems that the experience of fatigue reported by the patients is highly characterized by the consequences of their rheumatoid arthritis. Some patients described the characteristics of their fatigue as consequences of their disease. As for example, a lot of patients experienced that their fatigue is characterized by demanding increased physical effort to finish their commitments, work and all other activities that they wanted to do. They reported that they need more sleep during the day and thus struggle in planning and carrying on with their daily tasks.

"I have the feeling that it isn't normal because I barely manage my day. During the day, that I have to stop everything to sleep and need much more sleep than others" (participant 13, women, 26).

"For example if I had to go to someone's birthday today I wouldn't run around the garden for two hours this afternoon because that would finish me" (participant 5, women, 59).

Thus, the characteristics and the multidimensionality of RA fatigue seem to be linked to the consequences of rheumatoid arthritis.

3. 2. Consequences – fatigue affects every domain of life

Fatigue affects every aspect in the life of the patients in such a way that a lot of activities are reduced or impaired. They reported that every activity costs them a lot more effort than before their RA fatigue in comparison to people who are not experiencing fatigue.

"Household, cooking, cleaning. It is all impaired" (participant 15, women, 50).

"So I cannot go into the garden for an hour that is impossible. (...) Then I would be wiped out" (participant 4, women, 53).

Furthermore, patients reported that they are hindered in their work or study. They noticed that they need more time to finish their work because they work slower than before they were experiencing RA fatigue.

"Naturally it will be that I do things in the company slower. (...) If you always feel tired then you are probably slower" (participant 5, women, 59).

"I am studying longer because of it (fatigue) (...) so that I have more freedom to schedule my time to fit my needs" (participant 16, women, 22).

Also, a great number of patients get invalidity pension because they are not able to work anymore because of their rheumatoid arthritis symptoms, where fatigue also belongs.

Patients that are able to drive reported that they are afraid every time they drive a car. They have to prepare themselves mentally and physically to guarantee that they are fit to drive, because of the unpredictable character of their fatigue. They mentioned that they are worried about falling asleep while driving.

"I'd never drive a long distance if I wasn't fit. However you can't foresee it. Sometimes it comes at 10 o'clock in the morning" (participant 10, women, 58).

"I was always afraid when driving a car (...) if I'm on the passenger's side though it is fine (...) if you would have to drive yourself you would have to pull over. That wouldn't be possible anymore" (participant 10, women, 58).

High concentration is needed during driving and this may be problematic because according to the patient's, concentration difficulties are part of the physical consequences of their RA fatigue. Thus, every task they do either at home or at work, the patients experience difficulties because of their RA fatigue.

" (...) I get up at eight in the morning, (...) by half past eight I'll be downstairs for breakfast and then until half past eleven I be at the computer. But then I will lie down and sometimes I'll fall asleep. Then I'll sleep for half an hour or something. But I need this time so that I can be awake in the afternoon" (participant 1, women, 59).

The characteristics of fatigue may play a role in this. They struggle in completing the daily activities they do and some of these activities even trigger their fatigue or worsen it. As for example doing hard tasks, or tasks that demand a lot of effort from them. The characteristics of RA fatigue are for the most part responsible for their experienced consequences in their daily life, not only in activities.

Next, patients reported that the spontaneity in life is absolutely impaired because of the unpredictability and the variation in duration, frequency, severity and forms of fatigue. They have difficulties in planning their day and they cannot concentrate long enough to work efficiently. They must manage their time in a more flexible manner because of their fatigue or they must generally adapt a more flexible reaction pattern throughout their life.

" (...) That I am worse at planning: I'd like to drive somewhere or something (...). And then I think, oh man, later if something like that gets you. Then you get a little, just a few (...) concerns. You shy away from simply starting things" (participant 10, women, 58).

"You cannot really plan. You think: Oh it's possible and you (...) it would work normally. And suddenly you are so tired" (participant 10, women, 58).

Thus, patients must always base their decisions on their fatigue. If they have planned something, they must react in a flexible manner if their fatigue occurs. Patients reported that they have less vitality and have to work harder and slower on each task, costing them more effort than people without RA fatigue. They mentioned also that they need more breaks, which slows their activities and requires them to work for even longer hours.

"Work is also a lot more difficult for me. I have to take more breaks" (participant 2, male, 75).

For some patients this in turn results in the feeling that they cannot comply with the expectations of other people in their surrounding.

"You're missing the strength and you know you cannot accomplish what your environment expects from you. You can't do what your neighbor can do, whose house is always spic and span. You can't do what another person does who stands in the store all day or works all day. You simply know: I couldn't do that" (participant 4, women, 53).

They must always adjust their goals to their capacity and condition. This is not easy because it demands them to stop comparing themselves with other people who are not affected by rheumatoid arthritis related fatigue.

The patients also point out that they fail to fulfill their social roles because of the consequences resulting from their fatigue. The experience of fatigue restricted the patient's ability to fulfill their normal roles in the family.

"Even my children or (...). They don't know me like this. I was always a power woman. And then suddenly just stopping things and not being able anymore (...). Or when I want to do things with my grandchildren (...). That is so strenuous for me because I am suddenly so tired. Then I am not able anymore" (participant 10, women, 58).

They experience difficulties in providing support to their family members.

"When I'm tired I am not able to help. Then they have to do it themselves" (participant 9, women, 48).

One patient reported that she has a mother in law with diabetics and that she regularly supported her by providing her with medicine. Now she is not able to help and support her mother in law because of her RA fatigue.

"I used to help my mother-in-law when spraying but then I couldn't clean the kitchen as well because I wouldn't have been able to (...)" (participant 4, women, 53).

Social roles were also affected by rheumatoid arthritis related fatigue. Patients reported that they feel uncomfortable in receiving special treatment at work.

"Sometimes you have a day when you can't. Then you think in the morning: Oh just stay at home. You can't go to work but you think your colleagues might have the same problem. They might also be tired or something. Not just because I have this illness but because of that I get up and go to work" (participant 11, women, 62).

Patients also reported a restriction in their social life. They mentioned that they have to cancel appointments with friends and related others. They feel that they need rest because of their fatigue and are not able to engage in social interactions. Some reported that they even isolate themselves because they feel so fatigued that they need rest without any distraction.

"First you decided to visit your girl friends or something and then you don't want to anymore. Then you say, no I need some rest, I can't go there" (participant 9, women, 48).

"I have totally withdrawn myself. (...) I couldn't do anything. Going dancing wasn't possible, going out at all wasn't possible. So what do you do? You withdraw yourself" (participant 1, women, 59).

They also reported, that they are limited in their interaction with others because they get fatigued when they go out and have to go earlier at home.

"When I go out (...) then I can go jogging after dinner and then I am happy if I can go home already. I don't want to stay there because I am knocked out" (participant 11, women, 62).

Once again, this shows the link between the characteristics of fatigue and the consequences because of it. The unpredictability of fatigue and the variation in frequency, duration, severity and different forms of fatigue makes it difficult for the patients to have a social life as they imagine or as it was before their rheumatoid arthritis related fatigue.

Patients also reported that their fatigue has intense emotional consequences for them, leading to frustration, panic, a feeling of resentment, depression and isolation from others due to the lack of understanding.

"You cannot carry out an entire day, I can't do that. You get irritable as well" (participant 10, women, 58).

"I really don't know what these people want to grow old for. It is stupid. And then you also get a little depressed, so that you think: If I was dead, then I wouldn't have to have anything to do with all this anymore" (participant 3, women, 78).

Fatigue leads to a reduced level of self-esteem and the feeling of uselessness, guilt and the fear of being seen as lazy.

" (...) One simply feels useless. After the motto, now you might have done a lot but others could do much more than you in that moment. And you're tired of it already" (participant 4, women, 53).

"Yes, guilt trips. According to the motto, now you have to live down again. (...) You also don't like having to tell people that you need to lie down all of the time. (...) And then you think it might be convenience on your side. I always think (...) you're just too lazy" (participant 4, women, 53).

An interesting aspect worth pointing out is that more than half of the patients cannot specify their feelings with regard to fatigue.

"Feelings (...) I can't say that. I don't know it differently. It's like the pain. You don't have feelings about it anymore" (participant 1, women, 59).

It seems that this is adaptive for them because the feeling caused by their fatigue are too painful and would harm the patient's quality of life.

"I don't really think about that. If would think about that too much it would cause psychological stress and I'm not interested in that. I try to forget about it because I've built up this wall. I'm not going to let it touch me. I don't pay much attention to my illness" (participant 15, women, 50).

Thus, they pay no attention to their emotions with regard to fatigue in order to protect themselves. This is a successful strategy for them to reduce the emotional consequences. There are also patients who have neutral feelings about their fatigue and are still able to have effective self-management strategies and accept their condition.

"I have a neutral emotion towards it (...) I actually accept it. " (participant 16, women, 22).

A third group of patients seem to ignore their symptoms with regard to fatigue and go on as usual. They did not adapt to their condition but try to live as before their rheumatoid arthritis related fatigue.

"I've never felt that I've had any feelings towards it" (participant 12, women, 54)

"You have to stand above it and do something even though it hurts (physically)" (participant 2, male, 75).

Thus, the experienced emotional consequences seem to be linked with self-management strategies that the patients use to manage their RA fatigue.

3. 3. Self-management – is flexible

Patients reported trying a variety of self-management strategies. Some of them are focused on adapting to their RA fatigue through different strategies. One of it is acceptance. Patients reported that they accept their fatigue and so were able to adapt their goals better compared to those who did not accept their condition.

"(...) That I simply say, that is good, I allow the fatigue to overcome me and relax accordingly" (participant 10, women, 58).

"I believe I have accepted the thing with the fatigue. It's not the most important thing in my life. It is important (...) but not so extreme that I can't do anything (...) against it" (participant 16, women, 22).

Patients reported that they have learned to accept that they must adapt their behaviour to their fatigue by getting more rest.

"Over the years I have learned that one has their own pensum. And I have actually learned to accept it and to take time for it. If it isn't possible and simply to see how I can help myself to

improve. (...) I am trying to find my way for that now" (participant 13, women, 26).

Another coping technique identified was adopting a positive attitude toward life. Patients focus on the things that they are still capable of doing and think positive about this.

"If you always think negatively then the negative pain is always larger. So you must always think positively. Always positive no matter how bad you feel" (participant 12, women, 54).

"I have a few acquaintances who also have rheumatism and we see it a bit positively. So we always say, it is an illness but we can cope with it (...). You just have to think differently. And you learn how to think positively" (participant 15, women, 50).

Some responses from the patients can be interpreted that the patients are in the process of adopting such an attitude but have not reached a positive attitude yet.

"I think very positively and try to fight against it, I'm just not sure if I will succeed" (participant 15, women, 50).

There are also patients who reported that they have a positive attitude with regard to their fatigue but in the sense that they have to think positive. They reported that they do everything as before their RA fatigue and that they must think positive to survive through it.

"Yes if I only think about it, oh I'm so tired, I need to lie down or something. That's useless. You have to (...) get up and do something. I go outside or have work at home. I have to do that anyway. You can't leave everything lying around (...). Just try to think positive" (participant 11, women, 62).

Other patients reported that they had the feeling that they must think positive because of social pressure. They mentioned that the people in their surrounding expect that they think positive and that the patients think nobody will listen to their "cannot".

"Nobody wants to hear complaints. You have to stay positive. Nobody wants to listen to complaints constantly" (participant 12, women, 54).

The last two self-management strategies mentioned do not seem to be really positive thinking as known in the psychological setting. Still, the patients labelled it so. Patients reported that a negative attitude influences their self-management. They reported that they are less able to manage their fatigue effectively when they have a negative attitude with regard to their fatigue.

"If you think in a negative manner, then the negative pain is much worse" (participant 9 women, 48).

Thus, attitude plays an important role in the effectiveness of self-management.

Another self-management strategy that focuses on positive adapting to RA fatigue is benefit finding. Benefit finding is an effective self-management strategy that is reported by some patients. They reported that they listen more to their body, allow themselves to rest if they are fatigued and gain a more positive attitude towards life.

"I have learned to watch out for myself. Also to take care of myself. (...) To see the good in it" (participant 10, women, 58).

Furthermore, some patients report that they experience social support and use it to manage their fatigue.

"If you have someone who supports you and accompanies you in difficult situations it is a lot easier" (participant 12, women, 54).

A lot of patients struggle to remain positive in light of their fatigue. Some even have no sense of adopting a positive attitude towards life.

"My daughter says, Mama you have to think positively. And I say, be quiet now with your positive thinking. It is a trigger word for me. How am I supposed to think positively given my circumstances?" (participant 3, women, 78).

Nevertheless, benefit finding is an effective problem focused self-management strategy.

Patients reported using specific actions and distractions to manage their fatigue. Some of these actions are particularly rest, sleep or meditation.

"I just sit down sometimes or lie down, because I simply think that my eyes will close very soon" (participant 4, women, 53).

"Either I go into my room or (...) living room and shut down (...) or I simply close my eyes" (participant 9, women, 48).

Proper rest and sufficient sleep are often identified as strategies and related to effectively manage RA fatigue, according to the patients. Furthermore, they reported that they use alternative treatments such as homeopathy or acupuncture. Some even reported that they switched to a vegan diet because this helps them with their fatigue.

"I eat vegan, I've changed my diet. (...) I am a friend of alternative treatments" (participant 16, women, 22).

Others reported that they used food and drinks that make them more awake, such as coffee or guarana (a plant commonly used to reduce mental and physical fatigue and to increase energy).

"Well I've sometimes drank a strong coffee or something similar. It does get you up for a while" (participant 10, women, 58).

"Every time I get home I drink an espresso. And around 12 o' clock, when I have my break, I drink a large cup of coffee" (participant 5, women, 59).

Furthermore, many patients reported that they distract themselves from their fatigue through reading a book, listening to music or by going outside.

"I read or I just close my eyes or I listen to music" (participant 9, women, 48).

"You have to move. It's good for your joints which are affected by rheumatism and it's also good for the fatigue. Most importantly it is wonderful to be outside in the forest" (participant 5, women, 59).

Attention may also play a role. A patient reported that if she gives attention to her fatigue it will be much more present than if she ignores it.

"If you pay attention to it then it gets worse. If you direct your attention to something which is not your symptoms, then it isn't so bad" (participant 16, women, 22).

Patients manage their fatigue especially through rest, proper nutrition, and by paying no attention to their fatigue.

There are also self-management strategies that are less adaptive. Some patients made a choice to carry on regardless and accept the consequences. They go on until they have to rest to recover.

"If I have to do a lot, sometimes you have that, that you have to finish something, then I don't take the time to rest. But then I can completely forget the next day (...) I don't need to make plans (...) then I'm really off the mark" (participant 4, women, 53).

Patients also reported that they manage their fatigue by going on as usual. They maintain their goals and are not willing to adapt to their condition with RA fatigue.

"I suppress the fatigue until I'm done with everything that I wanted to do" (participant 5, women, 59).

"You just don't allow it (the fatigue) to take over. You can sleep when you make it to bed in the evening. (...) Everything must function, you shouldn't be ill" (participant 12, women, 54).

Furthermore, some patients reported that they pretend to be fine in the presence of other people. They will not show that they feel fatigued because of their RA. The reasons therefore are not clear. Maybe they do not want to be perceived as weak or they are simply ashamed.

"I'm not the guy who always tells everyone how miserable I feel. The others ask how I'm doing and then I say I'm fine. And if I say that I'm actually feeling bad and don't want them to know. And then you try to pretend that you're fine even though you're not" (participant 4, women, 53).

The less adaptive strategies could result in great physical and mental consequences for the patients. Their body is exposed to a permanent strain and they are not able to manage their goals adaptive to their condition. This may result in an on-going state of denial of their rheumatoid arthritis related fatigue.

Furthermore, some patients report that time played a role in self-management of fatigue. They said that they can manage their fatigue best if they have enough time available and can flexibly react to their fatigue.

"If I do an internship or when I will be working, (...) I believe my fatigue will be much worse. It is easier to schedule your time as a student" (participant 16, women, 22).

Work seems to play an important role here. Patients reported that if they would work less or be pensioned, they could manage their fatigue much better than now while they are working. They would have more free time available and could better divide their day in a manageable manner.

"If I wouldn't work, I would schedule my day differently" (participant 11, women, 63).

The patients that are working reported that they have no time at work to adaptively manage their fatigue. They cannot rest or sleep during their work.

"I fight it at work. I have to fight it. (...) I can't just lie down" (participant 10, women, 58).

This shows that the living conditions of an individual affected by RA fatigue has influence in managing RA fatigue. The strategies that the patients can use are dependent on the time and the living condition that they have.

They also report that if they can effectively manage their fatigue, they believe that they have some control on the situation..

"If I have a certain control over my fatigue? Yes I guess I do. I notice if I am getting tired and then I have to do something. Either I lie down or I fight the fatigue" (participant 11, women, 62).

Thus, by using self-management strategies in coping with their RA fatigue patients think that they have some self-efficacy.

3. 4. Communication – about fatigue is rare with health professionals and relatives

Most patients reported that they do not discuss their fatigue with health care professionals. The emphasis is therefore focused on physical symptoms, disease activity or the general health status.

"I cannot remember that that was ever a topic for conversation. There were always other, more important things" (participant 12, women, 54).

Furthermore, some reported that they did not want discuss their fatigue because it plays no important role in their life or because they did not want speak about their inability brought by

their fatigue.

"I don't speak about that because it isn't part of my life" (participant 16, women, 22).

"Sometimes you don't mention it. You don't always want to say, I'm tired, I can't today or something. You keep it to yourself sometimes" (participant 11, women, 62).

The patients choose to not discuss it because of the fear of being judged negatively, or labelled as lazy. Some also will not discuss it because they do not feel any sympathy from the health professionals. Another reason for not discussing fatigue with health professionals is regarding the available knowledge on RA fatigue. Some patients point out that they believe it is not discussed because fatigue, as a part of rheumatoid arthritis, has not been fully understood.

"I believe, that it isn't that familiar that it belongs to it. And that you don't associate it with rheumatism" (participant 16, women, 22).

"That is likely the reason why it isn't researched completely and that they don't know either what is going on" (participant 2, male, 75).

"I used to think it was because of my heart. My doctor said it wasn't. He still can't tell me where it comes from" (participant 8, women, 79).

The reasons why patients did not discuss their fatigue with health professionals seems to vary. Still, there are few patients who reported that they tried to discuss their fatigue with health professionals. However, they said it was simply dismissed by the professionals. The patients mentioned that the professionals would say that RA fatigue is "just how it is" without giving further information.

"Physicians like to say that it is simply the way it is. Nobody tells you what to do about it. (...) I wish that they would actually listen to me. Yes exactly, the rheumatologists (...) and not just say: It's the way it is. If they would actually listen and tell me about other possibilities. That's what I would like" (participant 10, women, 58).

Also, the health professionals attribute it to the medication, or would find other causes for the fatigue without explaining rheumatoid arthritis related fatigue in detail.

"I have told him that before but he said it would be because of all of the pills that I am prescribed" (participant 11, women, 62).

"He told me, you're not eating, that's why you're weak. Being so slender at your age, you don't have any reserves. And that's where your fatigue comes from" (participant 3, women, 78).

It is apparent that health professionals give few or no information to their patients that are willing to discuss their RA fatigue.

Furthermore, patients were asked about the communication with their family and friends. Most patients reported that they do not discuss their fatigue with neither their family or friends. Partly because they think that their fatigue is not an important theme to discuss.

"An acquaintance of mine has rheumatism as well. But we have never discussed the fatigue" (participant 6, women, 61)

"Oh I think, (...) it just isn't the topic. You have something else to talk about, it might be mentioned on the side" (participant 1, women, 59).

Another reason is because they do not want to be a burden to their family and friends, or because they are afraid of getting a negative reaction from them. They mentioned that they do not want to be misinterpreted and be called lazy.

"As well with my children or grandchildren, (...) I try not to annoy them with my feelings. I don't want to bother them" (participant 10, women, 58).

"Being scared of others saying that I am really lazy" (participant 4, women, 53).

Patients that discuss their fatigue with their friends and family reported that they bring this up in conversations in a general manner

"Yes also not being able to sleep at night, I do talk about that. But that I'm tired the whole day, that I cannot overcome the fatigue, I don't do that" (participant 8, women, 79).

Still, there are a few patients who reported that they try to seek for advice with regard to their fatigue.

"I exchange information about it, the best tricks (...). You basically just ask people what they are up to" (participant 13, women, 26).

They communicate with different people to get some helpful information about how they can effectively cope with RA fatigue.

Interestingly, most patients report that they are satisfied with their communication about their fatigue with their health professionals as well as with their family and friends.

"I don't expect anything else to be honest" (participant 5, women, 59).

Even if their fatigue is not discussed, they are satisfied with this. They will not change their coping strategies with regard to their communication about their fatigue. But the few patients that did discuss their fatigue with health professionals, or tried it, reported that they are very unsatisfied with the communication. They wish to be better informed about their fatigue and that the professionals should give more attention to their needs and understanding about what is happening with them. These patients wish that the professionals would give them some

advice about the management of fatigue

"Well to simply get more insight about the disease pattern, about the possible side effects for example fatigue. And that it is a topic at the doctor's as well as the disease pattern. And that they do tests past that and that they offer ways to treat it or do something at all" (participant 13, women, 26).

"Then I wouldn't have always felt so bad. And then I would have said, yes, it is normal for this disease pattern and fatigue simply belongs to it" (participant 4, women, 53).

In summary, it is surprising that a majority of the patients are not interested in discussing their fatigue with their health professionals or with their relatives. Only few patients reported that they do discuss it but that professionals ignore it or that they do it just in general terms. Still, most of the patients are satisfied with the communication, the reason therefore could be that the amount that do not discuss their fatigue reported that they are satisfied with leaving it be. The few patients that do discuss it wish that they would be better informed about what rheumatoid arthritis related fatigue is and how to more effectively cope with it.

4. Discussion

The aim of this study was to add more insight about fatigue as experienced by German patients with rheumatoid arthritis because it is not yet fully understood through proper research how it is experienced outside the US, the UK and the Netherlands. This seems to be an important domain of research to find out more about the apparent similarities or differences in different countries and to contribute to a better understanding of fatigue. It was expected that the results of this study would show similarities in the experienced characteristics and consequences of fatigue and differences in communication and self-management of fatigue with the studies conducted in the US, UK and the Netherlands. Furthermore, it was expected that the reason for the differences would be found in the differences in the national health systems. The samples of the forementioned studies and of this study are similar in terms of age, disease duration, educational level and marital status. In

respect to gender, it is less similar because of the homogeneous sample in this study.

The most prominent findings were that rheumatoid arthritis fatigue is experienced as multidimensional, manifesting in both a physical and mental form of fatigue and a type of fatigue that has certain triggers. To enumerate those mentioned during the interviews: social pressures, old age, RA, medication, weather, sleeping difficulties and strenuous tasks can trigger fatigue. Fatigue occurs due to a number of causes that are: RA, other physical conditions and medication. Furthermore, the consequences resulting from RA fatigue affect every aspect of a patient's life. Therefore, there are various approaches in self-management strategies and levels of success in managing fatigue with these strategies. Finally, it was discovered that professional support through effective communication is rare. In the following passages, the findings will be discussed in more detail.

First of all, the experiences of RA related fatigue was examined extensively. The characteristics of fatigue include: unpredictable, sudden, and cannot be reduced by rest. Furthermore fatigue is variable in duration, frequency and severity. These findings are consistent with the results from other studies in other countries (Swain, 2000; Benhamou, 2006; Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007; Nikolaus, Bode, Taal & Van de Laar, 2010a). A great number of patients complain that their fatigue being more demanding than pain and describe it as a chronic condition. This was also found in previous foreign studies (Van Riel & Repping-Wutts, 2009). Stufbergen and Rogers (1997) and Magnusson, Moeller, Ekman and Wallgren (2001) found that fatigue is known as a subjective, multidimensional and multicausal symptom of RA. These findings are consistent with the results from this study. The dimensions of fatigue identified in this study are: physical fatigue, mental fatigue and fatigue brought by different triggers (such as the ones mentioned above). The physical fatigue is characterized by heaviness, exhaustion and lack of energy, as was also found in the research from Treharbe, Lyons, Hale, Goodchild, Booth and Kitas (2008), Hewlett et. al. (2005) and Nikolaus, Bode, Taal and van de Laar (2010a). Mental fatigue can be compared to a lack in concentration. The prior reasons that trigger fatigue are: work, doing too much, not enough exercise, emotional stress, the weather that influences the mood, disturbed sleep and social pressure. These results are consistent with the hypothesis of this study about the similarities in characteristics of fatigue between

the different countries (the US, UK and the Netherlands). However, there were also a few visible differences. Participants reported that their fatigue is not triggered or caused by RA and pain, but rather on other physical impediments such as iron deficiency and ageing and even by medication. This is surprising because the literature shows that patients have difficulties in pointing out the exact causes for pathological fatigue (Nikolaus, 2012). The exact reasons therefore are unknown, but it could be said that the treatment and care in Germany is focused on medication to restore the disfunction of the immune system (Van Eijk, 2014) rather than informing patients about other symptoms as RA related fatigue. Furthermore, interdependency between the described characteristics of fatigue and the consequences of it was found. The main characteristics of fatigue often trigger consequences.

Therefore, the multidimensionality of fatigue plays an important role in experienced consequences, because of the variation in duration, frequency, severity and dimensions. It was found that fatigue affects every aspect of a patient's quality of life.. This was also found in previous research from the UK and the Netherlands (Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007; Nikolaus, Bode, Taal & Van de Laar, 2010a; Van Riel & Repping-Wuts, 2009). Albers, Kuper, van Riel, Prevoo, van T' Hof, van Gestel and Severens (1999) had already discovered in the late 90s that patients experience changes in work capabilities, rest during daytime, leisure time activity, transport mobility, housing and other activities. These findings are consistent with the results of this study that was conducted on a different population fifteen years later. Although at present, there is a lack of knowledge regarding the general phenomenon of fatigue, it can be said that the understanding of fatigue and its consequences has nonetheless improved through the years. Furthermore, it was found that the capacity to carry out daily tasks and responsibilities are hindered by RA related fatigue. This was also found in previous research from Flensner and Söderhamn (2003). Also, patients are impaired in their spontaneity in life because of the unpredictability of fatigue and the variation in frequency, duration and severity. Their fatigue requires everyday adaptation. Nikolaus, Bode, Taal and van de Laar (2010a) discovered that fatigue impairs patients in fulfilling their family and social roles. This is also true for the studies population in this study. Fatigue impairs the patient's capacity in spending active time with their family (family role) and complying with their social roles. It was also reported that social participation decreases

because of isolation and reduces the time spent in social participation as a result of RA fatigue. This was also found in previous research (Van Jaatsveld, Jacobson, Schrijvers, Van Albada-Kuipers, Hofman & Bijlsma, 1998; Nikolaus, Bode, Taal & Van de Laar, 2010a; Hewlett et. al, 2005). These results are consistent with the previous expectations of this study about the similarities in the consequences of fatigue between the different countries (the US, UK and the Netherlands). Differences were found in findings regarding the emotional consequences. They show that a great number of patients could not report such consequences. One possible reason is that fatigue does not represent an important part of patient's life and that the patient simply learned to accept it. It is a way of adapting by not attending to the emotional consequences of fatigue to protect them. It is also possible that patients are not fully aware of their symptoms and are not able to see the emotional consequences of RA fatigue. Regardless of the reasons, self-management seems to play a crucial role in it.

Patients use multiple forms of self-management simultaneously and with different levels of success. It was found that patients used emotional focused strategies as positive thinking but in two different ways. On the one hand, patients think positive about the abilities that they still have, as also found in other research (Hewlett et. al, 2005). On the other hand, patients think they behave the same manner they would before they began experiencing fatigue. In this case, the patients are less successful in adapting their goals to their actual situation. This was not found in previous studies. Another emotional focused strategy is acceptance of the situation. Patients reported that they have accepted their fatigue and the associated consequences. These patients have successfully adapted and matched their capacity with their goals. Furthermore, patients used problem-focused strategies to manage with their fatigue such as benefit finding. Nikolaus, Bode, Taal and van de Laar (2010a) found that benefit finding has positive effects on dealing with RA fatigue. This was also true for this study. Patients reported that they have learned to listen to their body, take more care of themselves and have adapted a positive attitude toward life. Other problem-focused strategies are sleep, rest, meditation, using alternative treatments and special nutrition and distract from fatigue through music, going outside or reading. These findings are consistent with other studies from other countries (Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007; Gronning, Lomundal, Koksvik & Steinbekk, 20011). Another

finding reveals the role of available time in self-management. The more time available, the more flexible patients can react to their fatigue and manage it more successfully. The living situation often determines how much time is available. If patients are working, they have less time compared to retired ones. Thus, the living situation influences self-management (Nikolaus, 2012). But it would also influence the characteristics of fatigue and the consequences. If living conditions change, then the characteristics of fatigue also changes in terms of duration, frequency and severity. This will have immediate consequences. However, there were also less adaptive management strategies found. Patients reported that they are willing to push themselves until they are physically unable to ignore their fatigue and then suffer from the consequences for several days. This was also found in studies from the UK and the Netherland (Hewlett et. al., 2005; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007). A reason could be that they are not accepting of their condition and are not able or adapt their goals. Another reason could be that they are not able to manage their fatigue in a more effective way.

It would be advantageous to implement an intervention that improves the relationship between management strategies and patients values and choices through an active role in the patients decision making process and increased support in the patients self-management (Van Eijk, Hustings, Kroes, Bessems-Beks, Ladewé & Vrijhoef, 2012). Implementing a proactive and focused health care system that focuses on the overall welfare of the individual would improve the support of self-management and patients decision-making process what will result in improved health outcomes for the patients (Van Eijk, Hustings, Kroes, Bessems-Beks, Ladewé & Vrijhoef, 2012). One opportunity to do so is to implement a multidisciplinary approach, with focus on clinical nurse specialists (Van Eijk, 2014) for the rheumatology setting (Tijhuis, Zwinderman, Hazel, Van deHout, Breedveld & Vlieland, 2002). They can act as an interface between patients and other health care professionals and thereby support patients in disease related problems such as support in self-management and patients decision-making (Van Eijk, 2014; Van Eijk et. al., 2012; Van Eijk-Hustings et. al., 2012). This could lead to an improved relationship between the used strategies and the patient's values and choices. Patients that are incapable of managing their fatigue could be provided with information and thereby learn new strategies that are congruent with their

values and choices.

Lastly, communication about fatigue with health professionals and related others was investigated. Most patients reported that they do not discuss their fatigue with health professionals and relatives because of various reasons (see results) and that they are satisfied with this. However, there are few patients who reported that they tried to discuss their fatigue and are unsatisfied about the communication with their health professionals because they feel that it was dismissed and underestimated. These findings are consistent with the results from previous research from other countries (Hewlett et. al., 2005; Swain, 2000; Flensner & Söderhamm, 2002; Repping-Wutts, Uitterhoeve, Van Riel & Achterberg, 2007). They prefer to be better informed about possible treatments and to be given advice on how to best manage their fatigue.

This agrees with the findings from Mühlhauser, Meyer and Steckelberg (2010). They saw that an increasing number of patients want to understand clinical research findings of new therapies. This should play an important role in the patient's decision-making and could influence the success of managing fatigue. However, a lot of health professionals think that sharing information with patients is too time consuming (Mühlhauser, Meyer & Steckelberg, 2010). Although, health professionals should be aware of the fatigue experienced by patients diagnosed with rheumatoid arthritis and should be able to explain fatigue as a symptom of their RA and that they through supportive self-management could live with it. Patients should always be given an opportunity to communicate their fatigue with their doctors without any burden and should be given information and advice if asked for. Having such an approach towards patients would improve the quality in chronic illness care. Therefore, a well-developed clinical information system that provides enough information to the patients and the health professionals is needed (Van Eijk-Hustings et. al., 2012). This will support the everyday activity of the patients and lead to a productive interaction between a team of well-trained health care professionals and informed patients (Van Eijk-Hustings et. al., 2012). In this sense, conducting special trainings in order to have professionally educated health professionals can be advantageous (Van Eijk-Hustings et. al., 2012), such as clinical nurses that specialize in rheumatology. Research shows that patients have the need for such nurses (Carney, 2015). In addition, Tjihuis et. al. (2002) found that patients with RA who had access

to a rheumatology nurse specialist acquire more knowledge and were also more satisfied with their care and treatment. Nurse's who specialize in rheumatology could support patients not only in decision-making and self-management, they could also improve a patients education and counselling (Van Eijk-Hustings et. al., 2012) by discussing with patients their experience with RA related fatigue in place of the rheumatologist. Another possibility to improve the communication between health professionals and patients is to include specific guidelines about communication within the established practical protocol or by improving coordination within the team of medical practitioners which could efficiently allocate and increase the time available for patients (Van Eijk-Hustings et. al., 2012). In summary, the results show the need for an implementation of a better framework for an ideal chronic illness care, such as the Chronic Care Model (see Figure 1).

In relation to the results and findings of the referenced studies, similar findings with a few deviations were found in this study regarding the different cultures in characteristics, consequences, self-management; and no differences were found in manners of communication. Similarities were found in the experienced characteristics and the multidimensionality of fatigue in patients from the UK, the Netherlands and Germany. Hewlett et. al. (2005) identify various triggers of fatigue in a English population that are comparable to the triggers found in this study. A significant difference is that the patients in this study identified medication as a cause of fatigue, which was something that was not mentioned in the previous studies. A reason could be that the German health system focuses on treatment with medication rather than by providing information. Most patients experienced fatigue as having far-reaching consequences and affecting many aspects of their life. This was also found in the previous studies. Another difference found is that most German patients did not mention emotional consequences because they chose to accept their condition in an adaptive approach to protect them from harm. Differences in self-management were found in the patient's ways of positive thinking and acceptance. It was found that patients use the strategy positive thinking differently. On the one hand, patients accept their condition and think positive about the abilities they still have. On the other hand, patients did not accept their condition and continue pursuing their daily goals until their body demands rest. To manage this, they need to think positive. They labelled this mentally as positive thinking but this perception differs

from a scientific definition as understood in psychology. Patients from the UK and the Netherlands reported a few similar self-management strategies as the patients in this study such as rest, distraction from fatigue, benefit findings and less adaptive strategies such as learning by trial and error and by “going on as usual”. Therefore, there is a need for a health system that provides support in self-management. Similarities were found in communication about fatigue. Most patients did not discuss it, but those who did felt that it was dismissed from health professionals. Having nurses who specialize in rheumatology who can inform and educate patients could help in correcting the shortcomings of their health professionals.

Limitations of this study is the homogeneous sample. The sample consists of 14 females and just one male. Thus, generalisation of the results is limited. Additionally, this study involved patients who reported that they experience fatigue regularly, but the inclusion of patients with rheumatoid arthritis in general could give more information about the phenomenon fatigue. Further a mixed inductive and deductive approach was used. Therefore, preexisting assumptions could have influenced the analysis and working process of this study. There were prior expectations regarding the results which may have influenced the analysis and reduced the objectivity of the researcher. Also one out of the two researchers coded the interviews. This could have limited the perspective with which the data was analyzed. It is recommended that two or more researchers analyse qualitative data to confirm the found results. The interviews were conducted by two different researchers. It is possible that the researchers asked different follow-up questions. Also, other factors such as the appearance or gender, tone of speaking and character of the interviewer can influence the patient's responses. This could have influenced the results. The setting in which the interviews were done could have also influenced the participants in their answers. Perhaps some patients found it too noisy or they felt that the space was not private enough to give honest answers. This could result to wrong data. Also, the participants were asked about their current experience with fatigue but research suggests that the characteristics of fatigue change over time. A longitudinal study design could provide more information to effectively explore the phenomenon of fatigue in more detail.

In future research, the relationship of experienced RA fatigue and the different health systems in Europe should be examined in more detail to be able to successfully analyse the

influence on experienced causes, self-management and communication. This is the first study that investigated the experience of RA related fatigue in Germany therefore further research should be done to confirm the results of this study. This was a qualitative study and did not test hypotheses about the differences in experiences of fatigue in different cultures. However, the results could be used in future studies to expand the conceptual model of Hewlett et. al. (2001). The findings in this study regarding how RA related fatigue is experienced in a German population could be used in creating an improved model of fatigue and could help develop a concrete theoretical model as more research is done in this field. Furthermore, the findings could be used to formulate a concrete definition of fatigue to allow for a consistent analysis and comparison with other studies that investigate RA related fatigue. Also, these results could be used in future quantitative research for use in Germany.

Medical interventions for RA related fatigue is not available yet, thus health professionals need skills and knowledge that enable patients to self manage their fatigue. To support a patient's self-management, it is necessary to understand fatigue from the patient's point of view, their experience of fatigue in RA, their beliefs about the causes and consequences, how they communicate about it and their coping strategies.

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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:

Inga Thieler
Tel. +4915116559867
i.thieler@student.utwente.nl

Anna Dermer
Tel. +4916097059598
a.dermer@student.utwente.nl

UNIVERSITY
OF TWENTE.

Appendix II – Informed consent

Informed Consent (German)

Inga Thieler und Anna Dermer, 2015

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 Müdigkeitserfahrung 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.

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

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

Appendix III – Interview scheme

Interview schema

''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. Um einen Eindruck der Intensivität ihrer Müdigkeit zu bekommen, möchte ich sie bitten vorab kurz diesen Fragebogen auszufüllen.''

''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?
- Leiden 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 insofern 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 Müdigkeitserfahrung 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 ineffektiv 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 Freunden, 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 Ihnen

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 Ihrer 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.”

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

Appendix IV - Coding scheme

1. Characteristics

Cognitive components

- Stress
- Motivation
- Recognition of fatigue

Physical components

- Draining
- Heaviness
- Overwhelming
- No energy
- Wearly

Character

- Eposidical
- Cronical
- Different forms of fatigue
- Unpredictable

Sleeping hygiene

Development

- Treatment in future
- Past
- Future
- Now

Duration

Frequency

Severity

- Worsen than pain

Triggers

- Aging

- Mental
- Sleep difficulties
- Doing (hard) tasks

Causes

- RA/Pain
- Medicine
- Physical

2. Consequences

Activities

- Work
- Household
- Limited in tasks

Consequences for others

Emotional

- Panic
- Frustration
- Irritable
- Feeling useless (self esteem)
- Resentment

Live on hold

- Cannot plan
- Need breaks
- Cannot concentrate
- Must manage time
- Work harder and slower
- Less vitality

Roles

- Social
- Family

Social interaction

- Isolation
- Less interaction

Social support

- Providing

3. Self-Management

Benefit finding

Attitude

- Positive thinking
- Pretend

Distraction/ Attention

- Read a book
- Listen to music
- Go outside
- Interact with people

Ignore fatigue (go on as usual)

Medicine, nutrition, non-prescription substances

Relax

Social support

- Receiving

Time available

Goal management

- Acceptance
- Goal maintenance

Self-efficacy

4. Communication

Discussed

Not discussed

Satidfaction