UNIVERSITITY OF TWENTE

# Communication about arthritis-related fatigue

## [Patient-related factors associated with the efficacy of communication about arthritis-related fatigue with the rheumatologist and other relevant healthcare professionals]

**Master's thesis**

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# Samenvatting

**Doel** Hoewel vermoeidheid veel voorkomt onder mensen met reumatische aandoeningen (RAs) en taalrijke problemen veroorzaakt in het dagelijkse leven, blijkt het een thema te zijn dat vaak niet besproken wordt tijdens medische consulten. Artsgerelateerde factoren die de communicatie belemmeren zijn al onderzocht in tegenstelling tot de patiëntgerelateerde factoren. Het doel van deze studie was het dus om een beeld te verkrijgen hoe effectief patiënten met RAs zich zelf inschatten met betrekking tot communicatie over vermoeidheid en patiëntgerelateerde factoren te onderzoeken welke deze communicatie mogelijk beïnvloeden. **Methode** 127 deelnemers met een RA, cross-sectioneel geworven via facebook en een reumaforum, hebben een online vragenlijst ingevuld. De vragenlijst bestaat uit vragen over demografische gegevens, vragen over de actuele situatie in communicatie over vermoeidheid met de reumatoloog of verpleegkundige en verschillende gevalideerde meetinstrumenten (Perceived Efficacy in Patient-Physician Interactions (PEPPI) schaal, Multi-dimensional Assessment of Fatigue (MAF) schaal, Health Assessment Questionnaire II (HAQ-II), Hospital Anxiety and Depression Scale (HADS), Brief HEXACO Inventory (BHI). **Resultaten** Zelfs niet de helft van de deelnemers (46.67%) zijn (zeer) tevreden met de communicatie over vermoeidheid met hun reumatoloog of verpleegkundige. 77.17% zeggen dat zij zelf de initiator zijn in communicatie over vermoeidheid. 26.77% praat alleen zelden of zelfs überhaupt niet over vermoeidheid met hun reumatoloog of verpleegkundige. Deelnemers lijken lager te scoren op de PEPPI schaal met betrekking tot gesprekken over vermoeidheid (gemiddelde = 16.15, SD = 4.25). Vier patiëntgerelateerde factoren geassocieerd met de waargenomen zelfeffectiviteit in communicatie over vermoeidheid met hun reumatoloog of verpleegkundige werden geïdentificeerd, namelijk, geslacht, vermoeidheid, fysisch functioneren en depressie. De beste predictor voor de uitkomsten op de PEPPI schaal is de tevredenheid van da patiënten met betrekking tot de actuele communicatie over vermoeidheid.

**Conclusie** De situatie in communicatie over vermoeidheid is nog steeds niet tevredenstellend en moet verbeterd worden. Patiëntgerelateerde factoren maken een verschil met betrekking tot de waargenomen zelfeffectiviteit in communicatie. Het causale verband tussen de tevredenheid van de patient en de waargenomen zelfeffectiviteit in communicatie over vermoeidheid moet onderzocht worden, omdat tevredenheid leidt tot betere gezondheidsuitkomsten.

# Abstract

**Objective** However fatigue is common among people with rheumatic diseases (RDs) causing numerous problems in everyday life, it seems that the issue of fatigue often remains undiscussed in medical consultations. Physician-related factors interfering the communication are already investigated opposed to the patient-related factors. Thus the aim of this study was to get insight in how effective patients with RDs perceive themselves regarding communication about fatigue and to investigate patient-related factors which possibly influence this communication. **Method** 127 participants with a RD, recruited via facebook and one forum for rheumatic patients, filled in an online survey. The survey consisted of demographic questions, questions concerning the current situation in communication about fatigue with the rheumatologist or HP, and different validated instruments (Perceived Efficacy in Patient-Physician Interactions (PEPPI) scale, Multi-dimensional Assessment of Fatigue (MAF) scale, Health Assessment Questionnaire II (HAQ-II), Hospital Anxiety and Depression Scale (HADS), Brief HEXACO Inventory (BHI). **Results** Not even half of the participants (46.67%) are (very) satisfied with the communication about fatigue with their rheumatologist or healthcare professional (HP). 77.17% stated to be the initiator in communication about fatigue. 26.77% talk only seldom or even never about fatigue with their rheumatologist or HP. Participants seem to score lower on the PEPPI scale regarding conversations about fatigue (mean = 16.15, SD = 4.25). Four patient-related factors associated with the perceived self-efficacy in communicating about fatigue with the rheumatologist or HP were identified, namely, sex, fatigue, physical functioning and depression. The best predictor for the outcome on the PEPPI scale is the patients’ satisfaction with the current communication about fatigue. **Conclusion** The situation in communication about fatigue still remains unsatisfactory and has to be improved. Patient-related factors make a difference regarding the perceived self-efficacy in communication. The causal association between the patients’ satisfaction and the perceived self-efficacy in communication about fatigue has to be investigated since patient satisfaction leads to better health outcomes.

# Introduction

This work was conducted in order to get more insight in the communication about fatigue between patients with rheumatic diseases (RDs) and their healthcare professionals (HPs). The motivation emerges from the fact that the physicians' or HPs' perspective has been investigated previously (Kim, Kaplowith, & Johnston, 2004; Zachariae, Pedersen, Jensen, Ehrnrooth, Rossen, & Von der Maase, 2003; DiMatteo et al., 1993; DiMatteo, Hays, & Prince, 1986) but the patients' perspective did not get much attention in past research. Thus, the purpose of this study is to investigate this perspective. Through exploration of some patient-related factors and their possible relation to the communication about fatigue with relevant HPs, it might be possible to make a start in taking both parties – HP and patient – into account with their respective responsibilities. Relevant HPs are rheumatologists and nurses because in the Dutch healthcare system these are the persons, from the medical encounter, with whom the patients can discuss disease-related issues such as fatigue.

The next paragraph is an overview about the different kinds and natures of RDs, a working definition of fatigue, and the actual situation of communication in medical care. Also, the impact of fatigue and the communication about it for patients with RDs is presented. Afterwards, patient-related factors that are hypothesized in literature to be related to fatigue-communication are described.

## Rheumatic diseases

Rheumatic diseases (RDs) is a collective name for more than 100 divergent diseases (Het Reumafonds, 2014). Often a degeneration of the joints causes pain and swelling or a dysfunction of a patient's immune system entails an overactive immune system acting against the body's own tissue (Guell, 2007; Tong, Jones, Craig, & Singh-Grewal, 2012). In the Netherlands, almost 2 million (≈11%) people are suffering from one form of RD (Het Reumafonds, 2014).

All forms of RDs are distributed into four main categories by the affected characteristic locations in the body (Holst & Meiser, 2009). (1) Inflammatory arthritis is characterized by inflammations of joints and the connective tissue causing pain, swelling and stiffness. The most prevalent form is rheumatoid arthritis. A degenerative form of RDs is (2) osteoarthritis. This form causes damage especially in the finger joints, the spine, the hip and, knees through deterioration causing pain and limitations in mobility. In (3) metabolic arthritis the rheumatic symptoms emerge from a dysfunction of the metabolism. The most prevalent forms of this type are gout, osteoporosis, and hemochromatosis. The last category is (4) soft-tissue rheumatism where muscles, ligaments, tendons and the articular capsule are affected, for example fibromyalgia. In this study all forms of RDs were included.

## Fatigue in RDs

In RDs, fatigue is the most burdening side effect of the chronic illness besides pain (Wolfe, Hawley, & Wilson, 1996; Carr, et al., 2003; Hewlett, et al., 2005). Several studies found prevalence rates of 40-80% in patients with different RDs (rheumatoid arthritis, ankylosing spondylitis, osteoarthritis) suffering from fatigue (Stebbing & Treharne, 2010). The main problem with fatigue is that it becomes a chronic state if it is not resolved (Repping-Wuts, Fransen, van Achterberg, Bleijenberg, & van Riel, 2007). Also, there are differences in types of fatigue, variations in duration, frequency, and severity of fatigued phases and it is frequently perceived as unpredictable (Hewlett, et al., 2005)

The causes of chronic fatigue in general are unknown until today (Repping-Wuts, van Riel, & van Achterberg, 2009) It is often described as a multidimensional concept with large impact on everyday life of suffering people. A popular definition that is frequently used in recent research is the definition 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'.*

The consequences of fatigue as a multidimensional concept, especially when it has become chronic, are not just physical but also emotional, social, and cognitive making the accomplishment of everyday activities more difficult. Repping-Wuts et al. (2003) found that, in addition to limited freedom of movement, chronic pain, joint pain, and limitations in daily life activities, fatigue belongs to the top five symptoms that patients describe as difficult to deal with. Patients often experience difficulties going to work or performing household activities. They are even restricted in the organization of their free time because chronic fatigue is often experienced as unexpected and uncontrollable. Additionally, patients are hindered in fulfilling their normal roles in social relations (e.g. family) (Hewlett, et al., 2005).

Since only little is known about treatment possibilities of fatigue most patients try self-management strategies to handle this problem. Usually, they try to solve emerging problems with ‘trial and error’ heuristics (Hewlett, et al., 2005; Repping-Wuts, Uitterhoeve, van Riel, & van Achterberg, 2008). Half of the participants of a study by Repping-Wuts et al. (2008) stated that using ‘trial and error’ is the best way to manage fatigue. Using this approach, individuals behave in a particular way to check whether this behavior is rewarding. Applied behaviors vary greatly among individuals. Some try to rest or relax while reading or listening to music for a while before resuming daily activities. Others carry on unless they are fatigued and accept the consequences afterwards. It was even found that some individuals try to cope with fatigue in their daily life by changing their attitude in a positive way by not complaining and getting on with it (Hewlett, et al., 2005; Repping-Wuts et al., 2008). Since the consequences of fatigue are affecting a persons’ whole life on physical, emotional, social and cognitive dimensions, communication about this issue is indispensible.

## Importance of effective communication about fatigue in patients with rheumatic diseases

In recent years, a development in medical care took place. Doctor-centered consultations changed more and more into patient-centered consultations (Visser & Wissow, 2003). Effective communication between patients and their HPs in a compassionate way has been proved to be beneficial for overall clinical outcomes. By Hojat, Louis, Markham, Wender, Rainowitz and Gonella (2011) it was found that physicians are able to cause patients to feel being important by behaving empathetic and this leads to better compliance which in turn causes more accuracy of physicians’ work and better health outcomes. According to Beller (2012, p. 1100) “compassionate care requires that providers be attentive and listen carefully to the patient’s concerns and truly desire to understand the patient’s perspective. It requires treating patients as individuals and not as diseases. When treating the whole person, providers are more likely to acquire an understanding of the psychological, behavioral, and social aspects of their patients’ health, and not just the physiologic or metabolic characteristics of their illness.” Empathetic engagement, listening and expressing desire to understand a patient is obviously not possible without communication – verbal and nonverbal.

The overall development in medical care consultations is that HP and patient now should form a team of experts treating the patients’ disease. The physician/HP is the expert in the medical encounter, but the patient is the expert in experiencing the disease (Haugli, Strand, & Finset, 2004). Working in a team means that all members have responsibilities. Despite the ongoing development, a prevalent attitude of physicians is that they think they know best what is best for their patients (Hawkes, 2009). Furthermore, available literature about patient-physician communication gives the impression that only the physician has the responsibility for good communication, not taking the patient’s part into account. Thus, from this point of view it might be possible to support the development of patient-centered communication through investigation of the patients’ perspective. Barriers to effective communication between patient and HP do exist on both sides (Faller, 2012). However, to the best of current knowledge, till today research generally focuses on what physicians/HPs can do to support good communication. This seems not sufficient as, according to literature, still too many patients with rheumatic diseases do not talk about their problems caused by fatigue with their rheumatologist or HP (Repping-Wuts et al., 2008; Hewlett, et al., 2005).

**Thus, this study investigates the current status in 2014 referring to the communication with relevant HPs about fatigue among patients with rheumatic diseases, as patients experience it. Do they communicate about fatigue, with whom, and are they satisfied with this communication?**

The consequences, barriers, and limitations patients with chronic fatigue experience often entail a lowered self-esteem which in turn may lead to feelings of uselessness (Hewlett, et al., 2005). Similar results were found by Feldthusen, Björk, and Mannerkorpi (2013). A self-image affected by feelings of helplessness, frustration, and shame seems to be associated with higher levels of fatigue, which in turn was found to be related to patients’ fear, caused by the uncontrollability of what is going on in their own body. A relationship between anxiety and fatigue was also found by Passik et al. (2002) as well as a relationship with depression (Collins, de Vogel-Voogt, Visser, & van der Heide, 2008). This study concerning two hundred cancer patients demonstrated that patients with higher levels of depression have more knowledge about existing interventions against fatigue, what might suggest that they are more likely to communicate about fatigue and ways to fight it. *This leads to the assumption that higher levels of anxiety and depression among patients with RDs may cause more communication about fatigue with HPs.*

According to existing literature, sociodemographic variables such as gender, age, and education also seem to play a role in patient's preferences to participate in medical communication (Arora & Mc Horney, 2000; Krupat, Yeager, & Putnam, 2000; Garcia-Gonzalez, Gonzales-Lopez, Gamez-Nava, Rodriguez-Arreola, Cox, & Suarez-Almazor, 2009; Farin, 2010; Faller, 2012). Female patients are more likely to prefer involvement in decision-making and seem to have a greater need in emotional support through HPs (Arora & Mc Horney, 2000; Krupat et al., 2000). Also, younger patients prefer a more active role in medical communication (Garfield, Smith, Francis, & Chalmers, 2007; Swenson, Buell, Zettler, White, Ruston, & Lo, 2004; Krupat et al., 2000; McKinstry, 2000; Hall & Roter, 2002). Additionally, in several studies, a higher educational level and a higher social status was found to be a predictor for a higher preference of participation in medical decision-making and communication (Garfield, et al., 2007; Swenson, et al., 2004; McKinstry, 2000; Schneider, Körner, Mehring, Wensing, Elwyn, & Szecsenyi, 2006). In a study by Collins et al. (2008) it was found that it makes a difference in experiencing fatigue if a patient lives alone or with a partner. People with a partner reported lower levels of fatigue than people living alone. A difference in preferences regarding active participation in medical consultations was found by Farin (2010) regarding age, level of education, and sex. Older, low educated women with lower income are less likely to prefer active engagement. *All these findings support the hypothesis that different sociodemographic variables play a role in experiencing fatigue and therefore there might also be an association between these variables and the patients' communication with HPs about their problems with fatigue. It can be assumed that these sociodemographic variables may be related to the experienced self-efficacy in communication of patients in medical consultations.*

Problems patients experience regarding fatigue causing distress differ in severity and dimension of interference with daily life. Patients who communicated about their fatigue related problems with a HP reported significantly higher levels of fatigue (Collins, et al., 2008). Accordingly, two ways of interpretation are possible. First it could be suggested that the severity may influence the communication about fatigue in that a higher level of suffering motivates patients to bring up the issue of fatigue in medical consolations and the patients may be more demanding. Second, more communication about fatigue may be a reason for higher levels of fatigue. It is possible that talking about fatigue causes the patients to think about it and to interpret minor symptoms in this direction. Furthermore, because of several findings of associations between the level of fatigue and disease related variables such as pain or general severity of disease, *the overall disease status is hypothesized to play a role in whether patients discuss fatigue with their HPs, meaning more symptoms lead to more communication about fatigue (Collins et al., 2008; Feldthusen et al., 2013; Pertl, Quigley, & Hevey, 2013; Shun, Lai, & Hsiao, 2009).*

Finally, the communication style is an expression of the persons' personality as De Vries, Bakker-Pieper, Konings, and Schouten (2011) stated. Reviewing the literature, the physicians' personality was already investigated and it was stated that it has a significant influence on the way of communication with their patients (Chapman, Duberstein, Epstein, Fiscella, & Kracitz, 2008; Lawrence, 2007). According to the suggestions of Chapman et al. (2008), physicians with higher scores on personality dimensions such as 'openness to feelings' and 'tender mindedness' learn more about the illness experiences of the patient and the person itself through communication. Furthermore, variables depending on the patient's personality such as aggressive behavior or noncompliance were found to evoke less directive communication of physicians (Chapman et al., 2008). There are a number of programs available for HPs to improve their communication skills which depend on their personality but can be improved through training. The patient's personality has not been sufficiently investigated yet in order to improve the communication between patient and HP. However, as the communication style is an expression of each person's personality, the patient's personality is likely to be as important as the physician's personality in medical consultations. Thus, the patient's personality was included in this study as a variable with possible influence on the communication with HPs about fatigue. As it is mentioned by De Vries, Ashoten & Lee (2009) people scoring low on the personality dimension 'honesty-humility' are prone to manipulate others to achieve personal goals, or people with a low level of 'extraversion' feel uncomfortable if they are the centre of attention. High 'conscientiousness' means working purposefully and highly emotional people have a great need for emotional support. *Thus, it is assumed that patients who differ regarding personality characteristics such as 'honesty-humility', 'extraversion', 'conscientiousness', or 'emotionality' also differ in their ability to get their physician to listen and to offer relevant information.*

**This study analyzes how patients evaluate their own efficacy in communication with their rheumatologist or HPs about fatigue, in order to investigate the relation of the abovementioned patient-related factors and the efficacy in communication.**

Within the treatment of RDs, fatigue represents a problematic issue in terms of communication. Until today, little is known about the communication between patients with RDs and their HPs about fatigue. However, it is well known that patients seeing their physician immediately sense if the other person does not actually listen to them, but focuses on other things than the current conversation (Beller, 2012). In a study about experiencing fatigue among adults with HIV conducted by Jenkin, Koch, and Kralik (2006), only three out of more than 400 participants were assisted by their HPs concerning their self-management techniques, suggesting that the actual situation regarding the communication over fatigue with HPs is not satisfactory. Patients seem to want to be asked about possible problems such as those related to psychosocial issues or side effects of the disease or medication. On the other hand, physicians wait until these issues are mentioned by their patients (Faller, 2012).

Thus, it can be summarized that patients who suffer from fatigue related to their disease experience great impact on their everyday life, but they are not aware of sufficient possibilities for assistance to deal with it. HPs are there to help so the question then arises, why patients do not ask for this help in many cases. Physician- or HP-related factors are well investigated, but poor communication still remains a problem in patient-physician communication in general and in particular about fatigue. Some patients bring up their problems with fatigue but many patients do not (Hewlett, et al., 2005)

**In this study patient-related factors which presumably influence the communication about fatigue among patients and their rheumatologists or other HPs are analyzed with the goal to get more insight in which factors may be related to the reluctance of patients to demand for help that is due to them.**

## Research Questions

Regarding the theoretical framework of the topic of communication about fatigue between patients with RDs and their HPs the following research questions were formulated:

1) *What is the current situation in communication about fatigue between patients and rheumatologists or HPs?*
    - Does fatigue come up for discussion during consultations?
    - With whom do patients discuss the issue of fatigue primarily?
    - Who brings up the subject of fatigue during the consultation?
    - Do the patients consider communication about fatigue with their rheumatologist/specialized nurse as important?
    - Are the patients satisfied with the actual communication about their fatigue?

2) *How effective do patients with rheumatic diseases consider themselves in the current communication with their rheumatologist or HP about fatigue?*

3) *Which of the following patient-related factors may be related to the perceived self-efficacy in communication about fatigue among patients with rheumatic diseases?*
    - Sociodemographic variables
    - Health status
        - Fatigue
        - Disease status
        - Anxiety and Depression
    - Patients' personality

# Materials and Method

## *Participants*

The participants of this study were 174 adults recruited via the internet or e-mail. All of them are diagnosed with a RD (self-reported) and had some experience with fatigue related to their disease. People without any experience of fatigue were excluded through an filter question, namely “Did you ever experience fatigue related to your rheumatic disease?”. Since the study was a voluntary online survey, an actual response rate could not be computed. A power analysis for correlation was conducted in order to estimate an appropriate number of participants and to detect small differences or relations (effect size = 0.3, $\alpha = 0.05$, power = 0.95). 111 participants were calculated to be sufficient for this study to draw reliable conclusions. In total, 174 patients took part in this study by filling in the online questionnaire. The data resulting from 127 fully completed surveys was used for the analysis. .

## *Procedure*

For this study, it was chosen to conduct an online-survey. The internet is an effective way to reach a broad range of people that come into consideration in a relatively short period of time. This was relevant because this study was conducted in the context of a master’s thesis which implies a limited amount of time. In order to get reliable results a relatively great number of participants was required.

In the Netherlands, there is an organization called ‘Arthritis Foundation’. The official name is ‘Stichting Nationaal Reumafonds’. It was founded in 1926 to support scientific research on rheumatism, informing, and educating about rheumatism, and to represent the interests of people diagnosed with an RD (Van de Laar, 2011). Contacting this organization for information about a successful recruitment strategy of participants provided one discussion forum (ReumaForum.nl - Vóór en door patiënten met reuma!) and two pages on Facebook being the page of the organization ‘Het Reumafonds’ and the page of a group called ‘Reuma En Dan’. For the actual recruitment, a ‘recruitment form’ was prepared (Appendix I). It included information about the purpose and the topic of this study. Additionally, patients were informed about the duration of filling in the questionnaire and that all their data would be handled anonymously. At the end of the form, the web link was given to the people to open the questionnaire. The original version of the ‘recruitment form’ is given in the appendix.

This form was posted in the forum under the topic ‘general’. This provided nearly no participants after one week. The structure of the forum required a post in all groups (one group for each form of rheumatic disease: rheumatoid arthritis, Sjörgens’ syndrome, polymalia rheumatica, systemic sclerosis, psoriatic arthritis, osteoarthritis, other rheumatic diseases) with the topic ‘Assistance sought for research – fatigue’.

On both of the Facebook pages, the ‘recruitment form’ was posted on the so called ‘pin board’, visible for all visitors of the sites. New posts are coming up on these pages frequently, causing the post with the survey to move downwards. Thus, it was updated after 6 days by commenting the post (Appendix II). This did not provide much more volunteers to fill in the questionnaire so the ‘recruitment form’ with the link was posted again after 24 days. Since the whole online recruitment provided not enough participants to draw reliable results, members of the patient forum ‘Reuma Research Partners’ were also asked to participate. The forum is a group of people with rheumatic diseases from the region Twente, Netherlands, supporting scientific research in this field. The members received the ‘recruitment form’ shown in the appendix I via e-mail.

The questionnaire started with a short introduction and participants were asked to give their consent to provide their data for this research through marking a field next to the following text: ‘I have read the information carefully, I understand, and I am content with participation in this research and the processing of the acquired data. I reserve the right to revoke this statement. Also, I reserve the right to stop participating in this study anytime.’

The actual questionnaire began right after the participants gave their approval with 7 demographical standard questions. Afterwards a filter question excluded patients without any experiences of fatigue. The instruments used to compose the questionnaire are described below. 174 participants opened the link to the questionnaire and 127 completed the whole survey so the survey was closed after six weeks between 9 May and 18 June 2014.

Ethical approval for this study was requested and received (6th April 2014) from the ethical committee of the behavioral science faculty of the University of Twente (Application number: 14139).

### *Instruments*

The questionnaire was composed with ‘Qualtrics’, an online survey software. The online questionnaire consisted of seven different validated instruments. Each of them will be described in detail in the following section. The research was carried out in the Netherlands so the questionnaire was written in Dutch and the validated Dutch versions of the already existing instruments were used. A complete version of the applied questionnaire can be found in the appendix (Appendix III).

## Demographic information

The questionnaire started with seven items about patients’ characteristics. The variables included age, gender, marital status (unmarried/not living together, unmarried/living together, married, widow/widower, divorced), education (none, primary school, lower level vocational training, lower level secondary general education, middle-level vocational training, higher level secondary general education, higher level vocational training, academic education), current life situation (full-time work, part-time work, household, school/study, unemployed, unemployable, retired), diagnosis (rheumatoid arthritis, osteoarthritis, S. L. E., fibromyalgia, systemic sclerosis, psoriatic arthritis, Reiter’s disease, gout, low back pain, tendinitis, osteoporosis, ankylosing spondylitis, other), and onset of disease.

## Actual situation in communication about fatigue

The part about the actual situation in communication about fatigue contained five items, listed below. These five questions were designed in order to get an overview of the opinion patients actually have concerning the communication about fatigue with their rheumatologist or HP. They were composed to show how many patients actually communicate about fatigue with their rheumatologist or HP. Also, the importance patients attribute to the communication about fatigue with their rheumatologist or a HP and their satisfaction about the actual situation referring to the communication about fatigue was subject to evaluation. Following the questions were listed, translated into English:

1) Do you talk about fatigue with your rheumatologist or HP?
2) With whom do you talk about fatigue especially?

3) Who brings up the issue of fatigue for discussion?
4) Do you think it is important to talk about fatigue with your rheumatologist or HP?
5) Are you satisfied with the actual communication about fatigue with your rheumatologist or HP?

### Perceived Efficacy in Patient-Physician Interactions regarding Fatigue (PEPPI-5 adjusted)

The original Dutch version of the Perceived Efficacy in Patient-Physician Interactions (PEPPI) (Maly, Frank, Marshall, DiMatteo, & Reuben, 1998) contained 10 items and was developed to measure the patients' competence to obtain medical information from the physician and to comprehend the provided information. For the purpose of this study, the original Dutch version of the PEPPI-5 (ten Klooster, et al., 2012) was slightly adjusted (Cronbach's α = 0.90). The statement of all questions remained the same as they were only adapted to the particular issue of fatigue. For example, the third item of the original PEPPI is "How confident are you in your ability to get a doctor to answer all of your questions?" whereas the adjusted item is "How confident are you in your ability to get a doctor to answer all of your questions concerning your fatigue?". A complete list of the adjusted items can be looked up in the appendix III. All five items began with "How confident are you in your ability to …" and the participants had to choose one out of five options ranging from "not at all confident" to "very confident". The greater the patient's perceived confidence of his/her ability the higher the score on this item. In order to analyze the obtained data, the scores of each item were summed up. Higher scores indicated a greater perceived competence to obtain and comprehend medical information in patient-physician interactions.

### The Multi-dimensional Assessment of Fatigue (MAF)

The Multi-dimensional Assessment of Fatigue was developed in order to measure four different dimensions of fatigue, namely severity, distress, interference in activities of daily life, and frequency and change during the previous week among patients with rheumatoid arthritis (Tack, 1991). In total, the scale consisted of 16 items (Cronbach's α = 0.91). Items 1 to 14 are questions like "How serious was the exhaustion that you experienced?" or "To what extent did the exhaustion hindered you from going to work?", and were answered through a numerical rating scale (NRS) (1-10). The options to answer the first item concerning the degree of fatigue during the previous week and the items 4 to 14 concerning the interference in activities of daily living ranged from 1 = “Not at all” to 10 = “A great deal”. The severity was measured by the second item with the NRS ranging from “Mild” to “Severe”. Item 3 was meant to measure the amount of distress participants suffer from (1 = “No distress” / 10 = “A great deal of distress”). For the last item, (16, “How did your exhaustion changed over the last 7 days?”) four answers were provided ranging from “Decreased” to “Increased”. Item 1 to 15 resulted in the Global Fatigue Index (GFI) by summing up the scores of item 1 to 3 plus the average score of items 4 to 14 and the transformed score of item 15 (transformed into a 1-10 scale by multiplying the score by 2.5). Item 16 is simply scored from 1 to 4. The GFI ranges from 1 to 50 with higher scores indicating greater fatigue severity, distress, or interference with activities of daily living (Hewlett, Dures & Almeida, 2011).

| **item** | **range of answers** | **form of item** | **result** |
|---|---|---|---|
| 1 | not at all – a great deal | NRS = numerical rating scale (1-10) | GFI = sum of item 1-3 plus average of item 4-14 plus transformed score of item 15 (1-50) |
| 2 | mild – severe | | |
| 3 | no distress – a great deal of distress | | |
| 4-14 | not at all – a great deal | | |
| 15 | 1-4<br>(transformed in 1-10 by multiplying 2,5) | score (1-10) | |
| 16 | 1-4 | simple score (1-4) | simple score (1-4) |

*Figure 1: The Multi-dimensional Assessment of Fatigue (MAF)*

### Health Assessment Questionnaire II (HAQ-II)

The Health Assessment Questionnaire II measures physical disability and was developed in order to provide a shorter measurement instrument for measuring physical functioning with a simpler scoring system being as good as the original HAQ. This scale is the best instrument in predicting mortality, work disability, joint replacement, and medical costs among patients with rheumatic conditions (Wolfe, Michaud, & Pincus, 2004). A validation study by Wolfe et al. (2004) found the HAQ-II to be at least as good as the original HAQ. The HAQ-II which was used in this study consists of 10 items (Cronbach's α = 0.89). Participants answer the items on a 4-point Likert scale (0 = 'Without any difficulty" / 3 = "Unable to do") with higher scores indicating more self-reported patients' disability. To acquire a reliable average score, at least 7 items have to be answered. A score of 0 indicates minimal loss of function while a score of 3 indicates complete disability (Wolfe et al., 2004; ten Klooster, Taal, & Van de Laar, 2008).

## Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale was developed in order to detect possible and probable anxiety disorders and depression among patients staying in a hospital clinic for a non-psychiatric reason (Snaith, 2003) A review by Bjelland, Dahl, Haug, and Neckelman (2002) suggested the HADS to be a valid instrument to assess the symptom severity and presence of anxiety disorders and depression. In this case, the Dutch version of the HADS (Spinhoven, Ormel, Sloekers, Kempen, Speckens & Van Hemert, 1997) was used to measure levels of anxiety (Cronbach's α = 0.84) and depression (Cronbach's α = 0.8). The scale consists of two subscales, one for anxiety and one for depression. Both subscales are independent measures and each consists of 7 items. The items were answered on a 4-point Likert scale ranging from 0 to 3 with higher scores indicating more possible or probable anxiety disorders and depression. The scores of the items were summed up for each subscale yielding an overall score range of 0 to 21 respectively with a cut-off point of 8+. Scores of 0 to 7 indicate normal levels of anxiety and/or depression (Snaith, 2003).

## Brief HEXACO Inventory (BHI)

The Brief HEXACO Inventory (BHI) is a short form of a personality test based on the six-dimensional HEXACO model (De Vries et al., 2009). Ashton and Lee (2007) found that the HEXACO model of personality exceeds the Big Five model by adding one important dimension of personality, namely Honesty-Humility. This dimension is meant to describe anti-social and self-serving behaviors (De Vries, 2013) which may be a personality characteristic with possible influence on a patients' communication style (De Vries, 2013). In total, the BHI contains 6 dimensions (honesty-humility, emotionality, extraversion, agreeableness, conscientiousness, openness to experience). Cronbach's α's for each subscale are listed in Table 1. With four items per dimension the total number of items is 24. Participants answered the items on a 5-point Likert scale with options ranging from 1 = "strongly disagree" to 5 = "strongly agree". For analysis, the scores were averaged per dimension resulting in 6 main scores for this scale (De Vries, 2013).

### *Reliability*

The reliability of the survey was controlled by calculating Cronbach's α for each (sub)scale (Table 1). For the scales PEPPI, MAF (the Cronbach's α for the MAF was only estimated with the first 15 items because the score of the 16$^{th}$ item stands alone), HAQII, HADS a high Cronbach's α from 0.890 to 0.913 were estimated. Low Cronbach's α were low for all subscales of the BHI ranging from 0.401 to 0.561.

*Table 1: Scale statistics*

| Scale/Subscale | Cronbach's α | # items | min | max | range |
|---|---|---|---|---|---|
| **Actual communication** | **-** | 5 | 1 | 4/5 | 1-4/5 |
| **PEPPI** | **0.897** | 5 | 0 | 4 | 0-4 |
| **MAF** | **0.913** | 16 | 0 | 10 | (0-10) |
| **HAQII** | **0.890** | 10 | 0 | 3 | (0-3) |
| **HADS** | **0.890** | 14 | 0 | 3 | (0-3) |
| HADS_Anxiety | 0.841 | 7 | 0 | 3 | (0-3) |
| HADS_Depression | 0.815 | 7 | 0 | 3 | (0-3) |
| **BHI** | **-** | 24 | 1 | 5 | (1-5) |
| BHI_Honesty-Humility | 0.487 | 4 | 1 | 5 | (1-5) |
| BHI_Emotionality | 0.406 | 4 | 1 | 5 | (1-5) |
| BHI_Extraversion | 0.561 | 4 | 1 | 5 | (1-5) |
| BHI_Agreeableness | 0.401 | 4 | 1 | 5 | (1-5) |
| BHI_Conscientiousness | 0.452 | 4 | 1 | 5 | (1-5) |
| BHI_Openness to Experience | 0.559 | 4 | 1 | 5 | (1-5) |

### *Data-analysis*

Statistical evaluation was conducted using IBM SPSS Statistics Data Editor 20. Descriptive statistics describe the means and frequencies of the samples' demographic data and the disease related characteristics, as well as to answer the first and the second research questions concerning the actual situation in communication about fatigue and the patients' perceived efficacy in communication during medical consultations. The frequencies of the PEPPI scale results were also plotted for visualization. The third research question was answered applying a correlation analysis to detect relations among the patient-related factors and the PEPPI at first instance. Subsequently, significant correlations were further investigated conducting a hierarchical regression analysis in order to investigate the predictive capacity of the factors, which were found to correlate with the results of the PEPPI scale. This way of analysis was chosen to examine different combinations of patient-related factors controlled for other patient-related factors.

# Results

## Sample

The number of participants who started the questionnaire through opening the URL was 174 but only 127 (72.99%) completed it. This was thought to be due to the included filter question regarding experiences with fatigue ("Did you ever experience fatigue related to your rheumatic disease?") However, surprisingly merely four participants dropped out at this point, what was possibly due to the fact that fatigue is widely spread among patients with RDs. Most participants stopped immediately after clicking on the link to the questionnaire without answering any question at all. Furthermore the dropout rate ranges from one to seven participants after each part of the questionnaire. After the part about the current communication and before the part regarding the self-efficacy in communication (PEPPI) 12 participants (25.53%) who did not complete the survey dropped out (Table 2).

*Table 2: Distribution of drop-out (127 out of 174)*

| **Moment of drop-out (after…)** | **N = 47** | **%** |
|---|---|---|
| Not started* | 14 | 29.79 |
| Demographic information (DI) | 5 | 10.64 |
| Filter question | 4 | 8.51 |
| Current Communication | 12 | 25.53 |
| Self-efficacy in communication (PEPPI) | 7 | 14.89 |
| Fatigue (MAF) | 2 | 4.26 |
| Disease status (HAQII) | 1 | 2.13 |
| Anxiety and Depression (HADS) | 2 | 4.26 |

*only opened the URL without answering any question

Since the study was a voluntary online survey an actual response rate could not be computed. The 127 participants of this sample were aged 64.72 years (SD=12.34) on average while almost 90% were females. More than 90% were medium or highly educated and about 60% of the participants were employed (full-time or part-time), homemakers or go to school or university, while one quarter was unemployable related to the RD. Most of them were living together with a partner (70.1%) (Table 3).

*Table 3: Demographics*

| Characteristic | mean | SD | range | n | % |
|---|---|---|---|---|---|
| **Age, mean ± SD** | 64.72 | 12.34 | 38-93 | 127 | |
| **Sex** | | | | | |
| Male | | | | 15 | 11.8 |
| Female | | | | 112 | 88.2 |
| **Education**[a] | | | | | |
| Low | | | | 10 | 7.9 |
| Medium | | | | 53 | 41.7 |
| High | | | | 64 | 50.4 |
| **Work situation** | | | | | |
| Full-time work | | | | 19 | 15.0 |
| Part-time work | | | | 39 | 30.7 |
| Household | | | | 14 | 11.0 |
| School/study | | | | 3 | 2.4 |
| Unemployed | | | | 7 | 5.5 |
| Unemployable | | | | 32 | 25.2 |
| Retired | | | | 13 | 10.2 |
| **Marital status** | | | | | |
| Living without partner | | | | 38 | 29.9 |
| Living with partner | | | | 89 | 70.1 |

[a] Low = none, primary school, lower level vocational training, lower level secondary general education; medium = middle-level vocational training, higher level secondary general education; high = higher level vocational training, academic education

Collected data regarding the participants' health status are listed in Table 4. On average, the participants were around the age of 51 at the moment of diagnosis. Most participants reported – while it was possible to chose more than one disease – to be diagnosed with rheumatoid arthritis (54.3%) followed by fibromyalgia (23.6%), osteoarthritis (18.9%), low back pain (15.7%), psoriatic arthritis (13.4%), and ankylosing spondylitis (9.4%). 23 participants stated that they suffer from another form of arthritis, not mentioned in the survey (Sjögren's syndrome (6), relapsing polychondritis (3),  atypical arthritis (2), palindromic rheumatism (2), reactive arthritis, Tietze's syndrome, scoliosis, Raynaud's phenomenon, Diffuse Idiopathic Skeletal Hyperostosis (DISH/Forestier's disease), Mixed Connective Tissue Disease (MCTD)). Two participants did not know the name of their disease.

*Table 4: Participants' health status*

| Characteristic | mean | SD | range | n | % |
|---|---|---|---|---|---|
| **Age at diagnosis** | 51.35 | 19.39 | 3-87 | 127 | |
| **Years since diagnosis** | 13.37 | 12.44 | 0-56 | 127 | |
| **Diagnosis** | | | | | |
| Rheumatoid arthritis | | | | 69 | 54.3 |
| Fibromyalgia | | | | 30 | 23.6 |
| Osteoarthritis | | | | 24 | 18.9 |
| Low back pain | | | | 20 | 15.7 |
| Psoriatic arthritis | | | | 17 | 13.4 |
| Ankylosing spondylitis | | | | 12 | 9.4 |
| Tendinitis | | | | 9 | 7.1 |
| S. L. E. | | | | 8 | 6.3 |
| Osteoporosis | | | | 5 | 3.9 |
| Gout | | | | 3 | 2.4 |
| Systemic sclerosis | | | | 1 | 0.8 |
| Reiter's disease | | | | - | - |
| Other | | | | 23 | 18.1 |
| **Don't know** | | | | 2 | 0.8 |
| **Fatigue (MAF)** | 33.91 | 6.80 | 14-44.73 | 127 | |
| **Physical functioning (HAQII)** | 1.19 | 0.56 | 0-2.5 | 127 | |
| **HADS** | | | | | |
| Anxiety | 7.01 | 4.06 | 0-17 | 127 | |
| Depression | 7.70 | 3.90 | 1-18 | 127 | |
| **Self-efficacy in communication (PEPPI)** | 16.15 | 4.25 | 7-25 | 127 | |

Participants were able to choose more than one disease they are diagnosed with. So it was possible to report some frequent combinations (Table 5). A combination of rheumatoid arthritis (9), osteoarthritis (11), and low back pain (14) with fibromyalgia are very frequent. Osteoarthritis was often present in combination with rheumatoid arthritis (11), and low back pain (9). The combination of rheumatoid arthritis and low back pain occurred 10 times.

*Table 5: Comorbidity – Patients with comorbid rheumatic conditions*

| | RA$^a$ | Osteo-arthritis | S.L.E. | Fibro-myalgia | Systemic sclerosis | Psoriatic arthritis | Reiter's disease | Gout | LBP$^b$ | Tendinits | Osteo-porosis | AS$^c$ | Other$^d$ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **RA$^a$** | | 11 | 2 | 9 | - | 3 | - | 1 | 10 | 3 | 1 | 3 | 8 |
| **Osteoarthritis** | | | 4 | 11 | 1 | 2 | - | 1 | 9 | 3 | 4 | 2 | 5 |
| **S. L. E.** | | | | 3 | - | - | - | - | 2 | 2 | 1 | 2 | - |
| **Fibromyalgia** | | | | | 1 | 2 | - | 2 | 14 | 6 | 2 | 2 | 4 |
| **Systemic sclerosis** | | | | | | - | - | - | - | - | - | - | 1 |
| **Psoriatic arthritis** | | | | | | | - | - | 3 | - | 1 | 2 | - |
| **Reiter's disease** | | | | | | | | - | - | - | - | - | - |
| **Gout** | | | | | | | | | 1 | 2 | - | - | 2 |
| **LBP$^b$** | | | | | | | | | | 6 | 2 | 3 | 4 |
| **Tendinits** | | | | | | | | | | | 1 | 2 | 2 |
| **Osteoporosis** | | | | | | | | | | | | - | - |
| **AS$^c$** | | | | | | | | | | | | | 1 |
| **Other$^d$** | | | | | | | | | | | | | |

$^a$RA = Rheumatoid arthritis, $^b$LBP = Low back pain, $^c$AS = Ankylosing spondylitis, $^d$Other: Sjögren's Syndrome in most cases (26.09%)

### *The actual situation in current communication*

Concerning the current situation in communication about fatigue between patients with RDs and rheumatologists or HPs it was found that about 11% never talk about fatigue during consultations despite they experience fatigue related to their RD. In most cases the rheumatologist is the person with whom the participants discuss their experiences with fatigue but the participants are the initiator of the conversation about fatigue in almost 80% of the cases. Although 74.81% estimate communication about fatigue as (very) important, not even half of the patients are (very) satisfied with the communication about fatigue with their rheumatologist or HP. Detailed results are listed in Table 6.

*Table 6: Frequencies – Current communication*

| Question | Answers | % |
|---|---|---|
| **Do you talk about fatigue with your rheumatologist or HP?** | Yes, very often. | 24.41 |
| | Yes, sometimes. | 48.82 |
| | Yes, but seldom. | 15.75 |
| | No, never. | 11.02 |
| **With whom do you talk about fatigue especially?** | Rheumatologist. | 40.16 |
| | HP. | 17.32 |
| | Rheumatologist + HP. | 24.41 |
| | Nobody. | 18.11 |
| **Who brings up the issue of fatigue for discussion?** | I, myself. | 77.17 |
| | My rheumatologist. | 3.15 |
| | My HP. | 7.09 |
| | Nobody. | 12.60 |
| **Do you think it is important to talk about fatigue with your rheumatologist or HP?** | Yes, very important. | 25.20 |
| | Yes, important. | 49.61 |
| | Neutral. | 14.96 |
| | No, not very important. | 10.24 |
| | No, not important at all. | - |
| **Are you satisfied with the actual communication about fatigue with your rheumatologist or HP?** | Vary satisfied. | 14.96 |
| | Satisfied. | 30.71 |
| | Neutral. | 29.13 |
| | Unsatisfied. | 18.90 |
| | Very unsatisfied. | 6.30 |

### *Self reported efficacy in communicating with healthcare professionals about fatigue*

The perceived efficacy of the participants in this study regarding patient-rheumatologist/HP communication about fatigue is normally distributed with a mean of 16.15 (SD = 4.25). In comparison to the literature the patients of this study perceive themselves as slightly less self-effective in communication with their rheumatologist or HP. The mean scores on the PEPPI scale in two studies involving people with chronic illness or disabilities (Henselmans, Heijmans, Rademakers, & van Dulmen, 2014) and people diagnosed with rheumatoid arthritis (Van der Vaart, Drossaert, Taal, Drossaers-Bakker, Vonkeman, & Van de Laar, 2014) ranged from 19.8 (SD = 3.6) to 21.8 (SD = 3.3). As mentioned above fatigue is proven to be a problematic issue in medical consultations. Thus the low mean score on the PEPPI scale in this study is probably due to the fact that in this study the perceived self-efficacy was measured in the specific case of communication about fatigue and not in the case of communication in medical interactions in general.

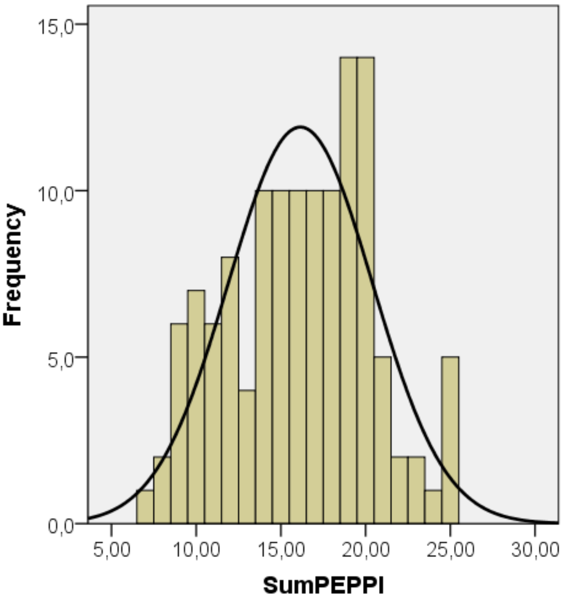

*Figure 2: Frequencies of the PEPPI sum score*

### *Patient-related factors related to the communication about fatigue*

The correlation analysis with the demographic and health status related variables as possible patient-related factors demonstrated four variables to be significantly negatively correlated with the PEPPI sum score. A small but significant negative correlation was found between the patients' sex and the sum score of the PEPPI (Table 7). Men perceive slightly more self-efficacy in communicating with their rheumatologist or HP about fatigue than women.

A stronger negative correlation was found for fatigue, physical functioning and depression. Less symptoms of fatigue, disease and depression were associated with a higher level of self-efficacy in communicating about fatigue with the rheumatologist or HP.

*Table 7: Pearson correlations – PEPPI sum score, demographic and health status related variables*

| | PEPPI | sex | age | age at diagnosis | education | work situation | matural status | fatigue | physical functioning | anxiety | depression |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **PEPPI** | 1 | -0.189* | -0.031 | 0.064 | 0.114 | -0.026 | -0.009 | -0.265** | -0.243** | -0.155 | -0.319** |
| **sex** | | 1 | 0.262** | 0.162 | -0.062 | 0.039 | -0.186* | 0.315** | 0.286** | 0.121 | 0.122 |
| **age** | | | 1 | 0.780** | 0.096 | -0.302** | 0.075 | 0.282** | 0.006 | 0.226* | 0.161 |
| **age at diagnosis** | | | | 1 | 0.075 | -0.251** | 0.077 | 0.192* | -0.106 | 0.160 | 0.170 |
| **education** | | | | | 1 | -0.014 | -0.131 | 0.006 | -0.142 | -0.060 | -0.073 |
| **work situation** | | | | | | 1 | -0.102 | 0,075 | 0.201* | 0.028 | 0.109 |
| **marital status** | | | | | | | 1 | -0.024 | 0.027 | -0.041 | -0.064 |
| **fatigue** | | | | | | | | 1 | 0.429** | 0.371** | 0.479** |
| **physical functioning** | | | | | | | | | 1 | 0.292** | 0.421** |
| **anxiety** | | | | | | | | | | 1 | 0.667** |
| **depression** | | | | | | | | | | | 1 |

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Further correlation analysis was conducted with the five categorical variables regarding the current situation in communication about fatigue. The results are listed in Table 8. One strong negative correlation with the PEPPI sum score was found, namely with the patients' satisfaction with the current communication. This correlation shows that the patients of this study, who are more satisfied with the current communication, are patients with a higher level of perceived self-efficacy in communication about fatigue with their rheumatologist or HP. The negative value of this correlation came about the fact that the dataset downloaded from 'Qualtrics' for analysis provided lower scores for more satisfaction among participants.

*Table 8: Spearman correlations – PEPPI sum score and variables regarding the current communication*

| | PEPPI | current com1[a] | current com2[b] | current com3[c] | current com4[d] | current com5[e] |
|---|---|---|---|---|---|---|
| **PEPPI** | 1 | -0.103 | -0.047 | 0.004 | 0.121 | -0.648** |
| **current com1[a]** | | 1 | 0.270** | 0.304** | 0.516** | 0.133 |
| **current com2[b]** | | | 1 | 0.470** | 0.195* | 0.117 |
| **current com3[c]** | | | | 1 | 0.378** | -0.045 |
| **current com4[d]** | | | | | 1 | -0.130 |
| **current com5[e]** | | | | | | 1 |

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Current com1[a] = Do you talk about fatigue with your rheumatologist or HP?
Current com2[b] = With whom do you talk about fatigue especially?
Current com3[c] = Who brings up the issue of fatigue for discussion?
Current com4[d] = Do you think it is important to talk about fatigue with your rheumatologist or HP?
Current com5[e] = Are your satisfied with the current communication about fatigue with your rheumatologist or HP?

The correlation analysis with the six dimensions of the BHI and the sum score of the PEPPI provided no significant relationships. The results are listed in Table 9.

*Table 9: Pearson correlations – PEPPI sum score and the personality dimensions of the HEXACO*

| | **PEPPI** | **honesty-humility** | **emotionality** | **extraversion** | **agreeableness** | **conscientiousness** | **openness to experience** |
|---|---|---|---|---|---|---|---|
| **PEPPI** | 1 | 0.124 | -0.136 | 0.049 | -0.093 | -0.003 | 0.048 |
| **honesty-humility** | | 1 | -0.042 | 0.119 | 0.165 | 0.135 | -0.069 |
| **emotionality** | | | 1 | -0.361** | -0.147 | -0.162 | -0.159 |
| **extraversion** | | | | 1 | 0.145 | 0.187* | 0.288** |
| **agreeableness** | | | | | 1 | 0.076 | 0.100 |
| **conscientiousness** | | | | | | 1 | 0.033 |
| **openness to experience** | | | | | | | 1 |

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

To further investigate the predictive value of the different patient-related factors with a relationship to the PEPPI sum score a stepwise hierarchical regression with three different models were estimated and all models are statistically significant (Table 10). The first model only includes sex as patient-related factor predicting the results on the PEPPI scale. As shown in Table 10 the predictive capacity for the PEPPI sum score of this model is 3.6% saying that men perceive themselves as slightly more self-effective in the communication about fatigue with their rheumatologist or HP.

Concerning the content and the high correlation among the factors regarding the patients' disease status (Table 7) the second model additionally considers the patients' level of fatigue, physical functioning and depression. This model accounts for 13.6% as predictor for the PEPPI sum score. The negative correlation among these predictors and the PEPPI sum score imply that more severe disease related characteristics indicate lower perceived self-efficacy in communication about fatigue. The predictive capacity from model one to model two significantly increases from 3.6% to 13.6%. However the best predictor in this model is depression since the variables sex, fatigue, and physical functioning are no longer significant. Thus, these insignificant patient-related factors do not have an additionally predictive value anymore, if depression is considered as a predictive factor.

The predictive capacity again increases significantly from model two to three. The third model, additionally including the satisfaction with communication as a variable, even predicts 43.4% of the outcome on the PEPPI scale. In this model only the added variable 'satisfaction with communication' showed to be a very good predictor for the PEPPI sum score, since all other variables (sex, fatigue, physical functioning, depression) no longer provide significant values for prediction. Thus, patients perceiving themselves as less effective in communication are less satisfied with their current communication about fatigue with their rheumatologist or HP. Consequently, it can be suggested that the satisfaction with the current communication is the best predictor for the perceived self-efficacy in communication about fatigue with the rheumatologist or HP.

*Table 10: Hierarchical regression*

| | Model 1 | | | | Model 2 | | | | Model 3 | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | $R^2 = 0.036$, F = 4.611, sig.= 0.034 | | | | $R^2 = 0.136$, F = 4.816, sig.= 0.001 | | | | $R^2 = 0.434$, F = 18.574, sig.= 0.000 | | | |
| Variabel | B | SE(B) | β | *p* | B | SE(B) | β | *p* | B | SE(B) | β | *p* |
| Sex | -2.476 | 1.153 | -0.189 | 0.034 | -1.459 | 1.187 | -0.111 | 0.221 | -1.263 | 0.965 | -0.096 | 0.193 |
| Fatigue[a] | | | | | -0.054 | 0.064 | -0.086 | 0.405 | 0.069 | 0.055 | 0.111 | 0.206 |
| Physical functioning[b] | | | | | -0.589 | 0.754 | -0.077 | 0.436 | -1.075 | 0.615 | -0.141 | 0.083 |
| Depression[c] | | | | | -0.252 | 0.109 | -0.232 | 0.022 | -0.118 | 0.090 | -0.109 | 0.191 |
| Satisfaction with communication[d] | | | | | | | | | -2.275 | 0.285 | -0.603 | 0.000 |

[a] Fatigue = MAF

[b] Physical functioning = HAQII

[c] depression = HADS_D

[d] Satisfaction with communication = current com 5

# Discussion

## *Main Findings*

Concerning the results of this study regarding the actual situation in communication about fatigue, the rheumatologist is the person with whom most of the patients discuss their problems in terms of fatigue if they do so. This was not expected since most patients feel dismissed by their rheumatologist when raising the issue of fatigue during consultations (Repping-Wutts et al., 2008; Hewlett et al., 2005). Furthermore, this study confirms that the patient is the initiator of conversations about fatigue during consultations with the rheumatologist or HP (Repping-Wutts et al., 2008; Hewlett et al., 2005). Even in this study, merely half of the participants are (very) satisfied with their current communication about fatigue, what represents an improvable situation.

An expected result of this study is that the patients who perceived themselves as more self-effective in communication about fatigue with their rheumatologist or HP are more satisfied concerning this communication. Previous literature shows that there are differences in how far patients want to be involved in communication and decision-making regarding their disease (Arora & Mc Horney, 2000; Östlie et al., 2007; Stinson, et al., 2008) but a recent study among patients with RDs (rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis) regarding shared decision-making by Nota et al. (2014) 59% to 63% preferred to be involved in decision-making processes. Furthermore, in accordance with this study, they found that patients experiencing less involvement than preferred, they are less satisfied with the decision-making process. Thus, the paternalistic model of medical consultations – meaning that the physician is providing information to the patient and the physician makes the medical decisions ‘only’ on basis of his/her expert knowledge (Knopf, Hornung, Slap, DeVellis & Britto 2008) – seems to slowly disappear.

In general the patients of this study seem to perceive slightly less self-efficacy in communication about fatigue than participants of other studies concerning general communication with rheumatologists or HPs (Henselmans, et al., 2014; Van der Vaart, et al., 2014) This is not surprising as self-efficacy in this study was estimated concerning the issue of fatigue. In previous research this issue has been proven to be especially problematic in patient-physician communication (Repping-Wutts et al., 2008; Hewlett et al., 2005).

With regard to the correlation analysis of the different patient-related factors and the PEPPI sum score, it was expected to find several correlations. Especially concerning the sociodemographic variables such as the level of education, marital status or work situation and anxiety as it was found in the literature (Garcia-Gonzalez, et al., 2009; Farin, 2010; Faller, 2012). As the sample of this study was heterogeneous and similar to samples of other studies using the PEPPI (Ten Klooster et al., 2011; Henselmans et al., 2014; Van der Vaart et al., 2014), the fact that some expected correlations were not found probably result from the adjusted version of the PEPPI scale, which was used in this study in order to investigate the patients' self-efficacy in communication about fatigue in particular. Concerning the analysis of possible relations between the PEPPI sum score and different personality characteristics, no conclusions can be drawn as all subscales of the BHI showed a low reliability. However, relatively low values for alpha reliability are common among short personality scales (De Vries, 2013). Two different samples were used to test the BHI. First a community sample and second a student sample consisting of undergraduate psychology and educational science students (De Vries, 2013). Both samples are not comparable to the sample of this study. That might be responsible for the very low reliability of the BHI results. However, personality already has been proven to be related to a person's communication style previously (De Vries et al., 2011).

The hierarchical regression provided unexpected results regarding sex and health status. In this study, men seem to perceive themselves as being more effective in communicating about fatigue with their rheumatologist or HP than women, while the opposite was expected (Arora & McHorney, 2000; Krupat et al., 2000). This unexpected result might be due to the fact that in this study only 15 male participants took part. However concerning sex such a distribution (female = 88.2%) is common among patients with RDs (Garcia-Gonzalez et al., 2009; Sleath, Callahan, Devellis & Beard, 2008).

As expected after reviewing previously published literature (Collins et al., 2008; Feldthusen et al., 2013; Pertl et al., 2013; Shun et al., 2009) a lower level of perceived self-efficacy in communication about fatigue with the rheumatologist or HP was also associated with more symptoms of fatigue, physical functioning, and depression. Previously, it was expected that more frequent conversations about fatigue are either caused by a higher level of suffering, which motivates patients to bring up the issue of fatigue, or that more communication about fatigue causes more reported symptoms of fatigue by drawing the patients' attention to it. These expectations emerged from the results of a study by Collins et al. (2008) stating that patients reported higher levels of fatigue if they discussed their fatigue-related problems with an HP. The results of the present study suggest that either a low level of perceived self-efficacy in communication leads to more symptoms of fatigue, physical functioning, and depression because of ineffective communication resulting in ineffective treatment, or that severe symptoms that are / cannot be treated appropriately lead to less perceived self-efficacy in patients concerning communication. In particular, it is known that it is difficult to provide qualified help for people suffering from fatigue (Haugli et al., 2004). Also, this fact can evoke the impression that the patient’s communication is not effective. Literature that could support these suggestions is not available yet. It is only known that better communication between patients and physician leads to better health outcomes (Hojat et al., 2011).

The best predictor for the outcome on the PEPPI scale is the patient’s satisfaction with the current communication about fatigue with the rheumatologist or HP since in the third model of the hierarchical regression the associations between the PEPPI sum score and the variables sex, fatigue, physical functioning, and depression are no longer significant in combination with satisfaction. As stated previously, more satisfaction concerning the current communication about fatigue indicates higher levels of perceived self-efficacy. Unfortunately it is not possible to draw causal conclusions from the results of this study concerning the association between the patients’ satisfaction and the perceived self-efficacy in the communication about fatigue. At this point logically it could be supposed that patients who are more self-effective in the communication are rather able to provide relevant information to the rheumatologist or HP and to get relevant information. This leads to higher levels of satisfaction because the communication is effective and presumably expedient. However, it is also possible that patients who are satisfied with the communication, for example because of the physician’s empathetic behavior (Hojat et al., 2011; Beller, 2012), they feel empowered and in succession they perceive themselves as self-effective in communicating about fatigue.

To the best of current knowledge, this is one of the first studies that really considers the patient as an essential part of an expert team, consisting of the patient and the physician, the patient as an active part, not only seeking help but having responsibilities for better health outcomes. The patient is the expert in experiencing the disease (Haugli, 2004), not the physician.

The physician or HP is dependent on the expert knowledge of the patient to provide adequate medical care. Thus, the patient also takes some responsibility for their own health outcomes. A patient who never mentions problems with fatigue cannot expect adequate assistance from an HP who does not even know that such problems exist, and this study showed that patients still often do not mention their problems in medical consultations. As it seems that the patient's perspective can be crucial in improving communication about problematic issues such as fatigue, this study eventually sets a starting point in investigating the patient's nature with regard to effective communication with the rheumatologist or HP about problems with fatigue.

### *Strengths and Limitations*

Besides the fact that most of the patients are female, the group of participants is heterogeneous. The survey was completed by a sufficient number of participants to draw reliable conclusions from the collected results. However, many of the participants (72.99%) who opened the link completed the whole questionnaire but unfortunately no information could be collected about the reasons for 27.01% of the participants to drop out at some point. Another limiting fact is that the survey was conducted online so only people actively using the internet were reached by this study. Thus, it was expected that rather younger patients would take part, but the recorded average age of the sample, which was 64.72, showed that this was not the case. In other studies the mean age of populations with RDs ranges from 52 to 60 years (Nota, Drossaert, Taal, Vonkeman & van de Laar, 2014; Garcia-Gonzalez et al., 2009; Sleath et al., 2008). However, there probably is a great number of patients suffering from fatigue that could not be reached via the internet.

Besides the standard questions and the five questions regarding the current situation in communication about fatigue with the rheumatologist or HP, only previously validated scales were used for investigation. However, even though the BHI is a validated scale it showed low reliability in this study, so the collected data could not be used for further analysis.

Nevertheless, to the best of current knowledge this study is one of the first investigating the patient's perspective in order to create a foundation for improvement of the communication between patients and physicians to get better health outcomes. Also, it shows once again that the actual situation especially in communication about fatigue between patient and rheumatologist or HP is improvable.

## *Conclusion*

Since the actual situation is still not satisfactory, more research has to be done in this field. With regard to this study, the patients' personality needs to be investigated further. From reviewing the literature, it is known that personality has a particular influence on a persons' communication style (De Vries et al., 2011), but in this case, the chosen scale to examine personality showed such a low reliability that no conclusions could be drawn from the results. However, four patient-related factors associated with the self-efficacy in communication about fatigue with the rheumatologist or HP could be identified. This implies that, besides the physician's perspective, there is another perspective, namely the patient's perspective which can be utilized to improve communication in medical consultations.

Scientifically, further research is needed to identify more patient-related factors that are associated with the way patients communicate with their rheumatologists or HPs. In future research it would be necessary to take care that the questioned people form a representative group, for example not only consisting of people who are actively using the internet. Certainly there is a great number of people suffering from RDs that is not familiar with the internet.

After identifying relevant patient-related factors, the underlying mechanisms have to be investigated in order to be able to develop programs or trainings. These are supposed to improve the patients' abilities to use existing resources for more effective communication in medical consultations in order to improve health outcomes.

The results of this study in comparison to previously conducted studies showed that perceived self-efficacy in medical communication seems to be lower when the conversation has to do with fatigue. Thus, it is necessary to actively include the patients and remind them of their responsibility in the teamwork that is ultimately supposed to lead to better health outcomes. Practically, this implies empowerment of the patient in communicating with physicians. This could be realized through communication training for patients. Furthermore, it can be supportive to inform the patient about the ongoing development in the medical encounter that patient and physician are supposed to form a team in managing the patient's disease. Thus, the patient needs to be informed that he/she is entitled to be heard by the physician, but also concurrently responsible for good management as well as the physician by providing relevant information and being demanding in what he/she needs.

◆

**This study is only the beginning as there is a lot to be done in this field of research.**
**To get the best results in the management of RDs and the accompanying symptoms, it is necessary to take the perspectives of all concerned persons into consideration.**

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# Appendix

## *I Recruitment form*

UNIVERSITEIT TWENTE.

Beste lid van het Reuma Research Forum,

U heeft zich aangemeld om aan onderzoek deel te nemen met betrekking tot reuma. Hiermee willen wij u uitnodigen voor een onderzoek naar de communicatie tussen patiënt en reumatoloog of reumaverpleegkundige over vermoeidheid bij patiënten met een reumatische aandoening.
Ik ben Caroline Cordesmeyer en ik heb zelf reuma sinds mijn 2e levensjaar. Nu ben ik 24 en psychologiestudent aan de Universiteit Twente in Enschede. Ik doe de master 'Gezondheidspsychologie' en op grond van mijn eigen ervaringen ben ik vooral geïnteresseerd in hoe mensen met chronische ziektes hun leven onder de knie krijgen. Op dit moment ben ik bezig met het schrijven van mijn masterthese en in deze context ben ik op zoek naar mensen met een reumatische aandoening die mij willen helpen door het invullen van een anonieme online vragenlijst.

Vermoeidheid blijkt naast pijn een groot probleem te zijn onder patiënten met reumatische aandoeningen. Toch blijkt uit de wetenschappelijke literatuur en ervaringsberichten van patiënten, dat er vaak niet over gesproken wordt. Ik ben geïnteresseerd in welke patiënt gerelateerde factoren zoals sociodemographische factoren, de gezondheidsstatus en de persoonlijkheid samenhangen met de communicatie over vermoeidheid. Ik wil dit graag onderzoeken om nieuwe perspectieven te ontdekken voor praktische aanbevelingen om de communicatie over vermoeidheid te bevorderen en daardoor het lijden van patiënten te verminderen.

Wilt u mij helpen meer inzicht te krijgen in het probleem van communicatie over vermoeidheid bij reumapatiënten?

Dan zou ik u van harte willen vragen om op onderstaande link te gebruiken om naar mijn vragenlijst te komen en in te vullen. Het invullen duurt hooguit 15-20 minuten en alle verkregen data wordt natuurlijk volledig anoniem verwerkt.
Als u van tevoren vragen heeft met betrekking tot dit onderzoek kunt u mij natuurlijk ook een email sturen.
Alvast bedankt voor uw deelname en uw ondersteuning voor mijn afstudeerproject!

Groet,
Caroline Cordesmeyer
c.cordesmeyer@student.utwente.nl

## *II Comments*

Comment on ‘Het Reumafonds’:

*Beste mensen, ik heb al enige vragenlijsten ontvangen. Bedankt aan diegene die mijn vragenlijst al hebben ingevuld. Ik heb er helaas nog een aantal ingevulde vragenlijsten nodig. Ik zou heel blij zijn als er nog meer mensen zijn die mij willen ondersteunen meer inzicht te krijgen in de communicatie over problemen met vermoeidheid bij mensen met reuma.*

Comment on ‘Reuma En Dan’:

*Leuk dat veel mensen interesse hebben aan mijn onderzoek. Ik heb al enige ingevulde vragenlijsten ontvangen maar ik heb echt nog meer nodig om een valide analyse te doen. Dus als iemand een idee heeft waar ik mijn link nog kan posten vertel maar! Bedankt aan diegene die mijn vragenlijst al heben ingevuld!*

*III Questionnaire*

# Vragenlijst

# Communicatie over vermoeidheid bij mensen met reumatische aandoeningen

## Demografische gegevens

1) Wat is uw geboortejaar?

☐☐☐☐

2) Wat is uw geslacht?

☐ man ☐ vrouw

3) Wat is uw burgerlijke staat?

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

4) Wat is uw hoogst genoten opleiding?

☐ Geen opleiding
☐ Basisonderwijs (lager onderwijs)
☐ Lager beroepsonderwijs (LBO, huishoudschool, LEAO, LTS, etc.)
☐ MAVO, (M)ULO, 3-jarige HBS, VMBO
☐ Middelbaar beroepsonderwijs (bijv. MTS, MEAO)
☐ 5-jarige HBS, HAVO, MMS, atheneum, gymnasium
☐ Hogere beroepsonderwijs (bijv. HTS, HEAO)
☐ Wetenschappelijk onderwijs (universiteit)

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

☐ fulltime werk
☐ parttime werk
☐ huishouden
☐ school of studie
☐ werkloos
☐ arbeidsongeschikt (WAO/WIA)
☐ gepensioneerd (AOW, VUT)

6) **Welke vorm(en) van reuma heeft u?**

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

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

☐☐☐☐

8) **Bent u wel eens vermoeid geweest als gevolg van uw reumatische aandoening?** **(Filtervraag, mensen die “Nee” kiezen zijn klaar met de vragenlijst.)**

☐ **Ja** ☐ **Nee**

## Communicatie over vermoeidheid

**De volgende 5 vragen gaan over de actuele situatie wat betreft uw communicatie over vermoeidheid met uw reumatoloog en/of verpleegkundige.**

**9) Praat u met uw reumatoloog en/of verpleegkundige over vermoeidheid?**

☐ **Ja, heel vaak.**
☐ **Ja, soms.**
☐ **Ja, maar zelden.**
☐ **Nee, nooit.**

**10) Met wie bespreekt u uw vermoeidheid vooral?**

☐ **Met de reumatoloog.**
☐ **Met de reumaverpleegkundige**
☐ **Met zowel de reumatoloog als de verpleegkundige.**
☐ **Met niemand.**

**11) Wie brengt het thema vermoeidheid (meestal) naar voren?**

☐ **Ik zelf.**
☐ **Mijn reumatoloog.**
☐ **Mijn reumaverpleegkundige.**
☐ **Niemand.**

**12) Vindt u het nodig om met uw reumatoloog en/of verpleegkundige over vermoeidheid te praten?**

☐ **Ja, erg nodig.**
☐ **Ja, nodig.**
☐ **Neutraal**
☐ **Nee, niet erg nodig.**
☐ **Helemaal niet nodig.**

**13) Bent u tevreden over hoe de communicatie over vermoeidheid met uw reumatoloog en/of verpleegkundige op dit moment loopt?**

☐ **Heel erg tevreden.**
☐ **Tevreden.**
☐ **Neutraal**
☐ **Ontevreden.**
☐ **Helemaal ontevreden.**

## Effectiviteit in Communicatie

**De volgende vragen gaan over hoe u met uw reumatoloog en/of verpleegkundige communiceert over vermoeidheid. Wilt u bij iedere vraag aangeven hoeveel vertrouwen u er in heeft dat u in staat bent om dit uit te voeren?**

**Hoeveel vertrouwen heeft u er in dat u …**

**14) … weet welke vragen met betrekking tot uw vermoeidheid u de arts en/of verpleegkundige moet stellen?**

**Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen**

**15) … in staat bent om de arts en/of verpleegkundige al uw vragen met betrekking tot uw vermoeidheid te laten beantwoorden?**

**Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen**

**16) … het bezoek aan de arts en/of verpleegkundige optimaal weet te benutten met betrekking tot uw vermoeidheid?**

**Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen**

**17) … in staat bent om de arts en/of verpleegkundige uw vermoeidheidsklacht serieus te laten nemen?**

**Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen**

**18) … in staat bent om de arts en/of verpleegkundige iets aan uw vermoeidheid te laten doen?**

**Helemaal geen vertrouwen ☐ ☐ ☐ ☐ ☐ Heel veel vertrouwen**

## Vermoeidheid

**De volgende 16 vragen gaan over uitputting als gevolg van vermoeidheid en het effect van uitputting op uw bezigheden. Omcirkel bij elk van de onderstaande vragen het cijfer dat het beste aangeeft hoe u zich gevoeld heeft in de afgelopen 7 dagen.**

**19) Heeft u zich uitgeput gevoeld?**

1 2 3 4 5 6 7 8 9 10

Helemaal niet Heel erg

**20) Hoe ernstig was de uitputting die u gevoeld heeft?**

1 2 3 4 5 6 7 8 9 10

Licht Ernstig

**21) Heeft uitputting u last (lichamelijk en geestelijk) bezorgd?**

1 2 3 4 5 6 7 8 9 10

Geen last Heel veel last

**Omcirkel nu het cijfer dat het beste aangeeft hoe uitputting u heeft belemmerd bij het kunnen uitvoeren van de onderstaande bezigheden in de afgelopen 7 dagen. Kruis het hokje links van het vraagnummer aan als u bepaalde bezigheden in de afgelopen 7 dagen niet heeft uitgevoerd om een andere reden dan uitputting (bijvoorbeeld u werkt niet omdat u met pensioen bent).**

☐ **22) Huishoudelijke taken en klussen in huis te doen**

1 2 3 4 5 6 7 8 9 10

Helemaal niet Heel erg

☐ **23) Te koken**

1 2 3 4 5 6 7 8 9 10

Helemaal niet Heel erg

☐ **24) Een bad / douche te nemen of u te wassen**

1 2 3 4 5 6 7 8 9 10

Helemaal niet Heel erg

☐ 25) U aan te kleden

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 26) Te werken

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 27) Op bezoek te gaan bij of tijd door te brengen met vrienden of familie

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 28) Seksueel actief te zijn

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 29) Aan vrijetijds- en recreatieve bezigheden

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 30) Boodschappen / een boodschap te doen

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 31) Te lopen

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

☐ 32) Beweging te nemen, lopen niet meegerekend

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Helemaal niet Heel erg

**33) Hoe vaak bent u in de afgelopen 7 dagen uitgeput geweest?**

- ☐ **Elke dag**
- ☐ **Meestal, maar niet elke dag**
- ☐ **Af en toe, maar de meeste dagen niet**
- ☐ **Bijna nooit**

**34) Hoe is uw uitputting veranderd in de afgelopen 7 dagen?**

- ☐ **Toegenomen**
- ☐ **Uitputting is op en neer gegaan**
- ☐ **Hetzelfde gebleven**
- ☐ **Afgenomen**

## Dagelijks functioneren

### Met betrekking tot de reumatische aandoening

Nu zijn wij geïnteresseerd in hoe uw ziekte van invloed is op uw functioneren in het dagelijks leven.

Kruis het antwoord aan dat het best beschrijft wat u meestal kon doen in de afgelopen 7 dagen.

| | zonder enige moeite | met enige moeite | met veel moeite | onmogelijk uit te voeren |
|---|---|---|---|---|
| 35) Kunt u opstaan vanuit een rechte stoel? | ☐ | ☐ | ☐ | ☐ |
| 36) Kunt u buitenhuis op een vlakke grond wandelen? | ☐ | ☐ | ☐ | ☐ |
| 37) Kunt u op en van het toilet komen? | ☐ | ☐ | ☐ | ☐ |
| 38) Kunt u een 1kg wegend voorwerp, zoals een pak suiker, bereiken en omlaaghalen van net boven uw hoofd? | ☐ | ☐ | ☐ | ☐ |
| 39) Kunt u auto-portieren openen? | ☐ | ☐ | ☐ | ☐ |
| 40) Kunt u in de tuin werken? | ☐ | ☐ | ☐ | ☐ |
| 41) Kunt u 15 minuten in een rij staan wachten? | ☐ | ☐ | ☐ | ☐ |
| 42) Kunt u zware voorwerpen verplaatsen? | ☐ | ☐ | ☐ | ☐ |
| 43) Kunt u zware voorwerpen optillen? | ☐ | ☐ | ☐ | ☐ |
| 44) Kunt u twee of meer trappen oplopen? | ☐ | ☐ | ☐ | ☐ |

**Met betrekking tot angst en somberheid.**

**Hieronder staan een aantal uitspraken, die door mensen zijn gebruikt om zichzelf te beschrijven. Kruis voor iedere uitspraak het vakje aan van het antwoord dat het beste weergeeft hoe u zich gedurende de laatste week gevoeld heeft.**

45) Ik voel me gespannen:

☐ Meestal
☐ Vaak
☐ Af en toe, soms
☐ Helemaal niet

46) Ik geniet nog steeds van de dingen waar ik vroeger van genoot:

☐ Zeker zo veel
☐ Niet zoveel als vroeger
☐ Weinig
☐ Haast helemaal niet

47) Ik krijg een soort angstgevoel alsof er elk moment iets vreselijks zal gebeuren:

☐ Heel zeker en vrij erg
☐ Ja, maar niet zo erg
☐ Een beetje, maar ik maak me er geen zorgen over
☐ Helemaal niet

48) Ik kan lachen en de dingen van de vrolijke kant zien:

☐ Net zoveel als vroeger
☐ Niet zo goed als vroeger
☐ Beslist niet zoveel als vroeger
☐ Helemaal niet

49) Ik maak me vaak ongerust:

☐ Heel erg vaak
☐ Vaak
☐ Af en toe maar niet te vaak
☐ Alleen soms

50) Ik voel me opgewekt:

☐ Helemaal niet
☐ Niet vaak
☐ Soms
☐ Meestal

51) Ik kan rustig zitten en me ontspannen:

☐ Zeker
☐ Meestal
☐ Niet vaak
☐ Helemaal niet

52) Ik voel me alsof alles moeizamer gaat:

☐ Bijna altijd
☐ Heel vaak
☐ Soms
☐ Helemaal niet

53) Ik krijg een soort benauwd, gespannen gevoel in mijn maag:

☐ Helemaal niet
☐ Soms
☐ Vrij vaak
☐ Heel vaak

54) Ik heb geen interesse meer in mijn uiterlijk:

☐ Zeker
☐ Niet meer zoveel als ik zou moeten
☐ Waarschijnlijk niet zoveel
☐ Evenveel interesse als vroeger

55) Ik voel me rusteloos en voel dat ik iets te doen moet hebben:

☐ Heel erg
☐ Tamelijk veel
☐ Net erg veel
☐ Helemaal niet

56) Ik verheug me van tevoren al op dingen:

☐ Net zoveel als vroeger
☐ Een beetje minder dan vroeger
☐ Zeker minder dan vroeger
☐ Bijna nooit

57) Ik krijg plotseling gevoelens van panische angst:

☐ Zeer vaak
☐ Tamelijk vaak
☐ Niet er vaak
☐ Helemaal niet

58) Ik kan van een goede boek genieten, of van een radio- of televisieprogramma:

☐ Vaak
☐ Soms
☐ Niet vaak
☐ Heel zelden

## Persoonlijkheid

**Hieronder staan weer een aantal uitspraken, die door mensen zijn gebruikt om zichzelf te beschrijven. Geef aan in hoeverre u overeenstemt met deze uitspraken.**

|  | Helemaal oneens | oneens | neutraal | eens | helemaal eens |
|---|---|---|---|---|---|
| 59) Ik kan lang naar een schilderij kijken. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 60) Ik zorg dat dingen altijd op de juiste plek liggen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 61) Ik blijf onaardig tegen iemand die gemeen was. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 62) Niemand wil graag met mij praten. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 63) Ik ben bang om pijn te lijden. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 64) Ik vind het moeilijk om te liegen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 65) Ik vind wetenschap saai. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 66) Ik stel ingewikkelde taken zo lang mogelijk uit. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 67) Ik geef vaak kritiek. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 68) Ik leg gemakkelijk contact met vreemden. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 69) Ik maak me minder zorgen dan anderen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 70) Ik ben benieuwd hoe je op een oneerlijke manier veel geld kan verdienen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 71) Ik heb veel fantasie. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 72) Ik werk erg nauwkeurig. | ☐ | ☐ | ☐ |  | ☐ |
| 73) Ik ben het snel met anderen eens. | ☐ | ☐ | ☐ | ☐ | ☐ |

**Helemaal**
**helemaal**

| | oneens | oneens | neutraal | eens | eens |
|---|---|---|---|---|---|
| 74) Ik praat graag met anderen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 75) Ik kan prima in m'n eentje moeilijkheden overwinnen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 76) Ik wil graag beroemd zijn. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 77) Ik houd van mensen met rare ideeen. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 78) Ik doe vaak dingen zonder echt na te denken. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 79) Zelfs als ik slecht behandeld word, blijf ik kalm. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 80) Ik ben zelden opgewekt. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 81) Ik moet huilen bij trieste of romantische films. | ☐ | ☐ | ☐ | ☐ | ☐ |
| 82) Ik heb recht op een speciale behandeling. | ☐ | ☐ | ☐ | ☐ | ☐ |

# Bedankt voor uw deelname!

Voor vragen of opmerkingen
stuur een email aan:
c.cordesmeyer@student.utwente.nl
Bij interesse is het via dit e-mailadres ook mogelijk om achteraf de resultaten van het onderzoek te ontvangen.

## *IV PEPPI – Original vs Modified Version*

| | **Original Version** | | **Modified Version (Fatigue)** |
|---|---|---|---|
| **How confident are you in your ability to:** | | **How confident are you in your ability to:** | |
| **1)** | …get a doctor to pay attention to what you have to say? | **1)** | …get a doctor to pay attention to what you have to say about your fatigue? |
| **2)** | *…know what questions to ask a doctor?* | **2)** | *…know what questions to ask your rheumatologist or HP about fatigue?* |
| **3)** | *…get a doctor to answer all of your questions?* | **3)** | *…get the rheumatologist or HP to answer all of your questions regarding fatigue?* |
| **4)** | …ask a doctor questions about your chief health concern? | **4)** | …ask the rheumatologist or HP questions about your chief health concern regarding fatigue? |
| **5)** | *…make the most of your visit with the doctor?* | **5)** | *…make the most of your visit with the rheumatologist or HP regarding fatigue?* |
| **6)** | *…get a doctor to take your chief health concerns seriously?* | **6)** | *…get the rheumatologist or HP to take your chief health concerns regarding fatigue seriously?* |
| **7)** | …understand what a doctor tells you? | **7)** | …understand what the rheumatologist or HP tells you about fatigue? |
| **8)** | *…get a doctor to do something about your chief health concern?* | **8)** | *…get the rheumatologist or HP to do something about your chief health concern regarding fatigue?* |
| **9)** | …explain your chief health concern to a doctor? | **9)** | …explain your chief health concern regarding fatigue to the rheumatologist or HP? |
| **10)** | …ask a doctor for more information if you don’t understand what he or she said? | **10)** | …ask the rheumatologist or HP for more information if you don’t understand what he or she said? |

* the cursive written items belong the PEPPI-5