



Bachelor thesis in completion of the bachelor mental health promotion at the faculty psychology of the University of Twente.

Titel:

Is there a negative influence of fatigue on Quality of life?

Supervisors:

Dr. E. Taal & Dr. C. Bode

Date:

June 2011

Author:

Amaia Borde Ondarra

Nurmistraße 36

48301 Nottuln, Germany

(t) 02502-25313

(e) a.e.bordeondarra@student.utwente.nl

Student number: 0202231

Table of Contents

| | |
|--|-----------|
| 1. Abstract..... | 1 |
| 2. Abstract (NL)..... | 2 |
| | |
| 3. Introduction..... | 3 |
| 3.1 Arthritis..... | 3 |
| 3.2 Fatigue..... | 4 |
| 3.3 Quality of life concept..... | 5 |
| 3.4 The relationship between fatigue and role-physical functioning..... | 6 |
| 3.5 The relationship between fatigue and social functioning..... | 7 |
| 3.6 The relationship between fatigue and role-emotional functioning..... | 7 |
| 3.7 The relationship between fatigue and mental health..... | 8 |
| 3.8 In summary..... | 9 |
| 3.9 Usefulness of the study..... | 10 |
| 3.10 Assumptions and Research questions of the current study..... | 11 |
| | |
| 4. Methods..... | 13 |
| 4.1 Participants..... | 13 |
| 4.2 Procedure..... | 18 |
| 4.3 The measure of fatigue..... | 18 |
| 4.4 The measure of health related Quality of life..... | 19 |
| 4.5 The measurement of pain..... | 24 |
| 4.6 Analysis..... | 24 |
| | |
| 5. Results..... | 27 |
| 5.1 Correlations among the concepts..... | 27 |
| 5.2 Explanatory power of fatigue..... | 29 |

| | |
|---------------------------------------|----|
| 6. Discussion | 35 |
| 6.1 Findings – Methodological reasons | 35 |
| 6.1.2 Findings – Content reasons | 36 |
| 6.1.3 Fatigue coping | 37 |
| 6.1.4 Social functioning | 39 |
| 6.2 Limitations of the study | 39 |
| 6.3 Implications | 40 |
| 6.4 Treatment options | 41 |
| 7. Conclusion | 44 |
| 8. References | 46 |
| 9. Appendix | 52 |
| 9.1 Appendix A: The SF-36v2 | 52 |
| 9.2 Appendix B: Scoring table SF 36 | 61 |

1. Abstract

Objectives. Fatigue is a commonly experienced symptom of patients with musculoskeletal diseases. The purpose of this study was to identify the extent to which fatigue interferes with the patients' physical and psychological quality of life while controlling for the effects of pain and physical functioning.

Methods. Participants were 207 patients with musculoskeletal diseases of an Outpatient clinic for Rheumatology in Enschede, the Netherlands. The correlation coefficients were calculated between four dimensions of health related quality of life, fatigue, pain and physical functioning. In addition, a two-step bloc wise regression analysis was conducted in order to find out what the unique informative value of fatigue is in the explanation of health related quality of life. In the first step, pain and physical functioning served as independent variables, while in the second step three dimensions of fatigue (fatigue severity, effect and coping) were attached as additional independent variables.

Results. Strong correlations were found between the four concepts of quality of life as measured by the SF-36. In addition, relative strong correlations were found between the independent variables, especially among the three dimensions of fatigue and between pain, fatigue severity and effect. After controlling for physical functioning and pain, fatigue explained between 4.2% and 8.2% of patients role, social and psychological functioning.

Conclusions. The current study indicates that RA related fatigue is – besides pain – an important factor in the explanation of patients health related quality of life. As RA fatigue affects quality of life, an intervention that improves the impact of fatigue might be expected to change the wider well-being of patients. A combined treatment of pain, physical functioning and fatigue is likely the most promising option for future RA treatment.

2. Abstract (NL)

Doelstellingen. Vermoeidheid is een algemeen ervaren symptoom van patiënten met aandoeningen van het bewegingsapparaat. Het doel van deze studie was om de mate waarin vermoeidheid interfereert met de patiënten fysieke en psychische kwaliteit van leven te identificeren, terwijl voor de effecten van pijn en fysiek functioneren werd gecontroleerd.

Methoden. De deelnemers waren 207 patiënten met aandoeningen van het bewegingsapparaat van een polikliniek voor Reumatologie in Enschede, Nederland. De correlatiecoëfficiënten werden berekend tussen de vier dimensies van de gezondheid gerelateerde kwaliteit van leven, vermoeidheid, pijn en fysiek functioneren. Daarnaast werd een twee-staps blok regressie-analyse uitgevoerd om erachter te komen wat de unieke informatieve waarde van vermoeidheid is in de verklaring van de gezondheid gerelateerde kwaliteit van leven. In de eerste stap, pijn en fysiek functioneren diende als onafhankelijke variabelen, terwijl in de tweede stap drie dimensies van vermoeidheid (vermoeidheid ernst, effect en coping) werden toegevoegd als bijkomende onafhankelijke variabelen.

Resultaten. Sterke correlaties werden gevonden tussen de vier concepten van kwaliteit van leven zoals gemeten door de SF-36. Daarnaast werden relatief sterke correlaties gevonden tussen de onafhankelijke variabelen, vooral bij de verschillende dimensies van vermoeidheid en vermoeidheid ernst, effect en pijn. Na controle voor fysiek functioneren en pijn, verklaarde vermoeidheid tussen 4.2% en 8.2% van de patiënten rol, sociaal en psychisch functioneren.

Conclusies. RA gerelateerde vermoeidheid is - naast de pijn - een belangrijke factor in de verklaring van de gezondheid gerelateerde kwaliteit van leven. Als RA vermoeidheid invloed heeft op de kwaliteit van leven, zou een interventie die de impact van vermoeidheid verbetert naar verwachting ook de rest van het welzijn van patiënten verhogen. Een gecombineerde behandeling van pijn, fysiek functioneren en vermoeidheid is mogelijk de meest kansrijke optie voor de toekomstige behandeling van RA.

3. Introduction

The following research will concentrate on established disabling musculoskeletal diseases in general and especially on Rheumatoid arthritis (RA).

Because fatigue proved to be an important but still neglected factor in RA treatment, the current study concentrates on this symptom in order to further strengthen the awareness that fatigue is a serious aspect of musculoskeletal diseases with far reaching consequences on the person's daily life. Because it turned out that fatigue is – besides pain – the most annoying symptom to handle (Hewlett et al., 2005), new knowledge about the relationship between fatigue and psychological and physical functioning might help to inform about new strategies and to improve existing treatments to combat fatigue.

I will include all forms of musculoskeletal diseases in my analysis, although most current explanation focus on RA and I will refer mainly to that literature. Thus, RA patients will be the focus of my interpretation efforts. This makes sense not only because most literature refers to RA, but also because RA patients constitute the majority of the actual study sample.

3.1 Arthritis

Arthritis is a term used to describe a group of conditions that is characterized by damage to the joints of the body, which results in symptoms as pain, swelling, stiffness and reduced movement. Today over 100 different forms of arthritis are known. The most common types of arthritis include Osteoarthritis, Rheumatoid arthritis (RA) and Gout (“Arthritis Basics”, 2005).

RA is a long-lasting systematic and chronic inflammatory disease which is causing joint pain, destruction and swelling. A result of the disease is that the immune system mistakenly attacks itself which leads to the swellings of the joints. The most frequently affected parts of the body involve the hands, wrists and knees. The inflammation may spread to nearby tissue and finally damage cartilage and bones. In the most severe cases of RA, the disease can also lead to a destruction of the skin, eyes, lungs or wrist joints (“Arthritis Basics”, 2005).

Around 1% of the population in western countries is affected by the disease and women are stricken three times more often (Lipsky, 1994).

3.2 Fatigue

The majority of the RA patients report – besides pain – a considerable amount of fatigue (Rupp, Boshuizen, Jacobi, Dinant & Van de Bos, 2004). Because of differences in the definition of fatigue and its measurement, prevalence rates vary between 42% and 80% in RA patients (Repping-Wuts, Van de Riel & Van Achterberg, 2008).

Affected individuals described fatigue as an “overall sense of tiredness and heaviness that was associated with a desire to sleep” and as “the kind of fatigue which one never recuperates from” (Tack, 1990). Other patients described fatigue as “an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work” (Repping-Wuts et al., 2008). Chronic fatigue can be constant or recurrent, it is not improved easily by sleep or rest and it can have considerable negative impact on the person’s quality of life.

Most RA patients report that fatigue is present on most days and that fatigue varies in intensity and frequency (Hewlett, Nicklin & Treharne, 2008). Affected people likewise described sudden and overwhelming “wipe outs” that come without warning. In general, two different types of fatigue are described by patients: fatigue can be experienced as heaviness or weight and as an extreme and overwhelming exhaustion which forces the patient to stop immediately his or her current activity and to lie down. This later form of fatigue usually has a sudden and dramatic onset and is experienced as unpredictable (Hewlett et al., 2005). Thus, patients clearly differentiated fatigue from “normal” tiredness as experienced by healthy individuals (Hewlett et al., 2005).

Furthermore, patients usually distinguish between a sort of physical and mental fatigue (Nikolaus, Bode, Taal & Van de Laar, 2010).

There seems to be a J-shaped curve in the strength of fatigue throughout the day: levels of fatigue become less in the course of the morning and increase to a peak in the late evening hours (Stone, Broderick, Porter & Kaell, 1997). Likewise, the characteristic course of the disease creates a J-shaped curve: the initial fall of medical complaints is due the instant benefits of treatment and the subsequent gradual increase of problems is due to the inability of contemporary medical treatments to fully suppress or prevent the damage of the joints (Pollard, Choy & Scott, 2005).

3.3 Quality of life concept

The quality of life concept used in the actual study calls for some further explanation. Originally, the concept of physical functioning is often used along with several other dimensions of role-, social and psychological functioning as an indicator of health related quality of life. In contrast, in the actual case, physical functioning is treated as a cause of impairments rather than an indicator of well-being per se. Thus, physical functioning served as independent control variable when I tried to understand the patients' quality of life impairments. For a good comprehension I will use the word quality of life to refer to the role-, social and psychological functioning of patients while excluding all forms of physical functioning. At the same time, one must keep in mind that this distinction is frequently not made in previous measurements and studies of health related quality of life with the consequence that this concept remains somewhat ambivalent.

3.4 The relationship between fatigue and role - physical functioning

The concept of role-physical functioning is used to refer to impairments in the fulfilment of daily roles as a consequence of disease related physical restrictions.

In a recent longitudinal study, it turned out that RA related physical fatigue and pain have a statistically significant relationship with limitations in physical activities of affected individuals. Patients who experience higher amounts of exhaustion and pain are especially likely to reduce physical activities (Rupp et al., 2004). Affected individuals report a loss of physical energy and a heightened need for rest (Hewlett, 2005). In line with this, the majority of patients state that they are constricted in their activities and their mobility because of fatigue (Nikolaus et al., 2010). Several RA patients report that physical play with their children is severely impaired and that fatigue in general constrains their ability to fulfil their normal roles within the family. The interviewed persons justified their reduced activity level by stating that they must preserve their restricted energy for the most important daily activities (Hewlett et al., 2008).

In addition, physical impairments due to fatigue are an important reason why numerous RA patients become unable to work. Increased physical impairments frequently lead to work disability which in turn is associated with considerable individual and economic harm. It has been assessed that RA accounts for round 2.5 billion dollar in lost wages each year (Kosinski, 2002).

In sum, on the basis of the current literature, I assume that level of fatigue and the ability to maintain daily roles associated with physical activity will compose a negative relationship in the current study.

3.5 The relationship between fatigue and social functioning

The concept of social functioning is used to describe patients' ability to sustain their social contacts and leisure activities.

In a study by Rupp et al. (2004) it was found that the maintenance of a social life is negatively influenced by physical fatigue, reduced activity, pain and depressive symptoms. Especially women felt that fatigue negatively influenced their social contacts because they regularly have to cancel appointments because they feel overwhelmed by fatigue (Nikolaus et al., 2010). Fatigue is a frequently mentioned cause to explain why RA patients give up enjoyable leisure activities and hobbies. Patients report that they feel that they must save their energies for the more essential duties of everyday life (Hewlett et al., 2008).

Several women likewise reported that fatigue makes it harder for them to help and support other people in their surrounding (Nikolaus et al., 2010).

In the light of these findings, I assume that I will find a negative relationship between levels of fatigue and the ability to maintain social contacts for RA patients.

3.6 The relationship between fatigue and role-emotional functioning

The concept of role-emotional functioning is used to describe the extent of limitations in the fulfilment of daily roles as a consequence of disease related emotional problems.

Role limitations due to negative emotions were found to be statistically significant correlated with symptoms of depression, pain, reduced activity and mental fatigue (Rupp et al., 2004).

The far-reaching consequences of fatigue reduce the patients' self-esteem, heighten irritability, bitterness and feelings of loss of control and usefulness (Hewlett et al., 2005). In addition, some women felt that they are unable to work in certain occupations while others stated that they are frequently tired and worn out at work which makes it difficult to concentrate (Nikolaus et al., 2010).

For this reason, I expect to find a negative relationship between fatigue and the fulfilment of daily roles as a consequence of emotional problems for RA patients.

3.7 The relationship between fatigue and mental health

Mental health is not alone indicated through the absence of psychological distress. Rather, mental health describes a state in which a person acknowledges his or her abilities, is able to cope with normal levels of stress and can productively work and contribute to the functioning of his or her community (“Mental health: strengthening our responses”, 2010).

RA patients who experience a considerable amount of fatigue are likely to report worse mental health than the general population. A possible explanation is that restrictions due to fatigue in an array of life domains give rise to a broad array of negative emotional consequences. Frustration, irritability, loss of control, bitterness and tearfulness are often experienced by RA patients (Hewlett et al., 2008).

A recent qualitative study indicated that especially younger women with several daily roles reported negative emotions as a response to RA fatigue (Nikolaus et al., 2010). Women described their condition as “being oversensitive, becoming irritated more quickly, not being able to deal with things or being catty” (Nikolaus et al., 2010). Furthermore, women reported that they are frequently angry, in a bad or sad mood, feeling miserable, rebellious, frustrated, anxious, self-pitying and misunderstood (Nikolaus et al., 2010).

Overall, mental health was found to be negatively associated with depressive symptoms and mental fatigue (Rupp et al., 2004). Depression, which is frequently related to a higher level of fatigue, is assumed to be present in at least 25% of all RA patients (Frank, Beck & Parker, 1988).

However, because of an overlap of symptoms in depression and RA (such as fatigue, insomnia or less appetite), it is still challenging to reliably assess depression in RA patients and results must be interpreted with some caution (Blalock & DeVellis, 1992).

In general, greater trait anxiety is likely to exaggerate the effects of fatigue (Mancuso, Rincon, Sayles & Paget, 2006). Likewise, people with a history of mood disorders, such as depression or generalized anxiety, run a higher risk to experience a considerable amount of fatigue (Filfield, McQuillan & Tennen, 2001). Poorer mood in everyday life and daily stress also increase fatigue experiences (Schanberg, Sandstrom & Starr, 2000).

Likewise, the perception that RA will have severe negative consequences is usually followed by increased fatigue (Treharn, Lyons & Hale, 2008). Similarly, lower self-efficacy and perceived personal control over the course of the disease give rise to more complaints regarding fatigue (Brekke, Hjortdahl & Kvien, 2001).

Thus, current research suggests that I will find a negative relationship between fatigue and the general mental health of RA patients.

3.8 In summary

RA patients report considerable diminished functioning and overall well-being compared to the general population (Kosinski et al., 2002). Disease related fatigue turned out to be a key determinant in patients' health related well-being. In a recent study, fatigue explained between 1% and 14% in the variance of RA patients' health related quality of life (Rupp et al., 2004). The consequences of fatigue seem to permeate into every sphere of life. Many activities are reduced extremely or are stopped completely. Patients undergo restrictions in everyday tasks, in the work domain and leisure activities (Hewlett et al., 2008). Many RA patients believe that fatigue restricts them in housekeeping, gardening and childcare (Hewlett, 2008). Affected people likewise struggle to maintain social engagements and close relationships (Hewlett et al., 2008).

3.9 Usefulness of the study

Because currently there is no well-established treatment that prevents or cures RA, the primary management aim is to reduce disability in RA patients and improve their overall quality of life (Pollard et al., 2005).

In general, fatigue is likely to aggravate pain and disability. When treatment addresses fatigue, a wider cluster of symptoms is likely improve as a consequence (Hewlett et al., 2005).

Nevertheless, both patients and medical professionals still lack knowledge about how to best manage fatigue and actual treatment primary concentrate on pain release (Repping-Wuts et al., 2009).

In line with this, current treatment primarily leads to an improvement in the physical functioning and pain experience of RA patients. Attendances for the improvement of emotional health and well-being are less well developed (Kosinski, 2002). Thus, further understanding of the social and emotional aspects of the disease become now increasingly important.

One can conclude that it is necessary to collect more information about the nature of fatigue and its relationship with health related quality of life. More needs to be done to optimise the effects of treatment which partly depends on the routine measurement of disease's impact. Additional knowledge about fatigues influence of quality of life might be used to further strengthen the awareness that fatigue is a severe symptom which should be addressed in RA treatment. Likewise, more knowledge about the relationship between fatigue and quality of life might help to develop new strategies to combat fatigue and to refine existing treatments.

3.10 Assumptions and Research questions of the current study

The examination is based on the assumption that those individuals who experience higher amounts of fatigue will also report lower levels of health related quality of life and those patients who have more negative quality of life experiences on a regular basis will likewise experience more fatigue. Thus, I expect that data will reveal a bidirectional relationship between fatigue and four selected dimensions quality of life (role-physical functioning, social functioning, role-emotional functioning, and mental health).

To test my assumption, the subsequent examination intends to answer the following general research question: Is there a negative relationship between fatigue and health related quality of life?

In order to make this question more specific, four sub questions should be examined:

1. Is there a negative relationship between fatigue and role-physical functioning in patients with musculoskeletal disease?
2. Is there a negative relationship between fatigue and social functioning in patients with musculoskeletal disease?
3. Is there a negative relationship between fatigue and role-emotional functioning in patients with musculoskeletal disease?
4. Is there a negative relationship between fatigue and general mental health in patients with musculoskeletal disease?

Pain and/or physical functioning might operate as a third variable in the explanation of the relationship between fatigue and impairments in the daily functioning of RA patients.

Physical functioning and bodily pain will serve as control variables in the analysis because current literature suggests that fatigue correlates strongly with both pain and impaired physical functioning. Pain and disability, as fatigue, negatively affect the patients psychological condition, social functioning and general feeling of well-being (Katz & Yelin, 1993). In addition, fatigue generally correlates with depressive symptoms, pain, disturbed sleep, increased physical effort and psychosocial factors (Huyser et al., 1998).

Thus, pain, physical functioning and fatigue along with several other factors are likely to form an interrelated bundle of RA symptoms that are difficult to separate from one another. In addition, each symptom is likely to have multiple causes. A combination of variables might be the underlying cause of both fatigue and related daily life impairments.

The question is whether fatigue as a separate variable adds informative value to the explanation of RA symptoms detached from the effects that pain and physical disability induce. Although little is yet known about the indirect effect of these items, there seems to be widespread consensus over the far-reaching impact of fatigue on the daily life of affected individuals.

4. Methods

4.1 Participants

Altogether 207 patients in an Outpatient clinic for Rheumatology participated in the original survey. Overall, the sample consisted of 69 men and 138 women with collectively 12 different diagnoses. Fewer men than women participated in the survey which may reduce the generalizability of the results. However, the spreading of the sample nearly corresponds to the epidemiological distribution in RA as women are more often affected by the disease than men (Lipsky, 1994).

The mean age of the actual participant sample was 56 years (SD= 14. 92) with an age range from 19 years of the youngest participant to 93 years of the oldest participant. The average disease duration was about 12 years (SD=11.49).

Table 1: Sociodemographic and disease characteristics of the study population (N=207)

| Variable | n | % |
|-------------------------|---|------|
| Gender | | |
| Men | | 33.3 |
| Women | | 66.7 |
| Age | | |
| 19-30 | | 4.8 |
| 31-40 | | 9.7 |
| 41-50 | | 17.9 |
| 51-60 | | 30.0 |
| 61-70 | | 20.3 |
| 71-80 | | 13.0 |
| 81-93 | | 4.3 |
| Disease duration | | |

| | |
|----------------------------------|------|
| 0-10 | 59.2 |
| 11-20 | 22.3 |
| 21-30 | 12.1 |
| 31-40 | 2.9 |
| 41-50 | 1.9 |
| 51-60 | 1.5 |
| Disease distribution | |
| RA | 52.2 |
| Fibromyalgia | 7.2 |
| Osteoarthritis | 20.8 |
| Bechterew disease | 5.3 |
| Psoriatic arthritis | 7.2 |
| Articular gout | 6.8 |
| Back pain | 4.8 |
| Osteoporosis | 4.3 |
| SLE | 1.0 |
| Tendinitis | 0.5 |
| Scleroderma | 0.5 |
| Reiter`s syndrome | 0.5 |
| Other | 9.2 |
| Marital status | |
| Unmarried/living alone | 10.1 |
| Unmarried/living with sb. | |
| Married | 8.7 |
| Widower/ Widow | 64.3 |
| Divorced | 11.6 |

| | |
|------------------------------------|------|
| Unknown | 4.8 |
| | 0.5 |
| Number of children | |
| No children | |
| All children moved out | 19.9 |
| Children at home ^a | 51.5 |
| Children at home ^b | 14.6 |
| Unknown | 14.1 |
| | 0.5 |
| Education level | |
| No apprenticeship | |
| Basis education | 1 |
| Lower work education ^c | 10.1 |
| MAVO, (M)ULO ^d | 23.2 |
| Middle work education ^e | 19.8 |
| 5 year school ^f | 21.3 |
| Higher work education ^g | 8.2 |
| University | 11.1 |
| Unknown | 4.8 |
| | 0.5 |
| Working situation | |
| Fulltime Work | |
| Part time Work | 19.3 |
| Household | 19.3 |
| In education | 15.0 |
| Out of work | 1.9 |
| Inability to work ^h | 2.4 |

| | |
|-------------------|------|
| Pensioners | 15.5 |
| Unknown | 26.1 |
| | 0.5 |

a = all children are 15 years or older. b= at least one child is younger than 15 years. c=LBO, home economics course, LEAO, LTS etc. d= 3 year HBS, VMBO. e= for example MTS, MEAO. f= HBS, HAVO, MMS, secondary school. g= for example HTS, HEAO. h= WAO/WIA.

Table 1 indicates that the biggest group in the sample consists of RA patients, followed by fibromyalgia, osteoarthritis, Bechterew disease, psoriatic arthritis, articular gout, back pain and osteoporosis patients (N=223). The remaining four disease patterns (SLE, Tendinitis, Scleroderma and Reiter's syndrome) are to a marginal extent present among the participants (n=5).

As shown in table 1, the majority of the participants in the current study are married and a substantial percentage has at least one child (80.2 %). Among those participants that have offspring, around half of them no longer have children living at home. This finding is probably explained through the fact that a greater percentage of older participants with adult offspring participated in the current study.

As indicated in table 1, the education level of the participant sample is fairly regular distributed, with relatively few participants without any apprenticeship and relatively few participants with a university degree.

Comparatively many participants work full or part time (38.6%), while few are students or out of work. A considerable amount of all participants are unemployable. This condition might be a result of the patient's musculoskeletal disease. This explanation seems reasonable, since RA is a crucial risk factor of becoming unemployed (Kosinski, 2002). About a quarter of the participants are pensioners. This is very likely a consequence of the relative high age of the actual sample.

4.2 Procedure

Before they had their appointment with the rheumatologist, all patients were asked if they were willing to participate in the current study. There was no money paid for the participation and we have no information about which patients for what reasons refused to participate in the study. Altogether, 207 patients filled in questionnaires on a computer via a touch screen in a Rheumatology clinic in the Netherlands.

Participants answered questions about demographic variables (sex, age, education, working situation and marital status), disease related information (condition, disease duration), pain, general well-being, functional restrictions, health related quality of life and fatigue.

4.3 The measurement of Fatigue

As qualitative research indicates, fatigue has several dimensions that are experienced to varying degrees by different patients (Hewlett et al., 2005). For this reason, an instrument which assesses the three dimensions of fatigue (severity, its impact and the perceived ability of patients to cope) independent from one another, is best suited to capture the multidimensional nature of fatigue.

Research indicated satisfactory criterion and construct validity of the three visual analog scales used in the current study (Nicklin et al., 2010), which makes them suitable measurement tools for the current purpose.

Three 100 mm visual analog scales with two descriptive anchors were used to measure the severity of fatigue, its effect and the patient's ability to cope with it. The following questions were provided:

Severity: "tip with your finger on the place of the line to indicate your overall severity of fatigue over the last seven days (0= no fatigue, 100= "Absolutely no energy at all")."

Effect: "tip with your finger on the place of the line to indicate the overall effect of fatigue for you over the last seven days (0=no effect, 100= very strong effect)."

Coping: "tip with your finger on the place of the line to indicate your overall ability to cope with fatigue during the last seven days (0= absolute not good, 100= very good)."

4.4 The measurement of health related quality of life

In order to measure health related quality of life, the second version of the SF-36 was used (see Appendix A). The SF-36 questionnaire turned out to be practical, reliable and a valid tool for measuring physical and mental well-being (Hewlett, Hehir & Kirwan, 2007). In general, it is assumed that the questionnaire can be completed within five to ten minutes. The SF-36 questionnaire is a generic health survey because it can be used across age groups (the only requirement is that participants must be 18 years or older) and across different diseases and treatment conditions.

Overall, the questionnaire consists of 36 questions that measure physical functioning and mental health from the patients' point of view.

Items are grouped into 8 scales: Physical function (PF), role-physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role-emotional (RE) and mental health (MH). For the purpose of the current study, four of the eight subscales of the SF-36 were analysed in more details in order to explore the patients' health related quality of life (the RP, SF, RE, MH scales). In addition, the PF scale serves as independent control variable.

The eight scales of the SF-36 survey were selected from initially 40 scales used in a Medical Outcomes Study. The actual eight scales were shown to represent the most widely measured concepts in health surveys. In

addition, these concepts were most likely to respond to varying courses of the disease and to treatment (Pollard et al., 2005).

Chronbach's alpha was calculated in order to check for the internal consistency and reliability of the four constructs of quality of life that are measured by the SF-36 (RE, SF, RP & MH) as well as physical functioning, which serves as control variable.

Chronbach's alpha reliability coefficient ranges from 0 to 1, whereby values closer to 1 indicate greater internal consistency of the items in a scale. George and Mallery (2003) provide the following rules of thumb to rank Chronbach's alpha:

$\alpha > .9$ = excellent, $\alpha > .8$ = good, $\alpha > .7$ = acceptable, $\alpha > .6$ = questionable, $\alpha > .5$ = poor, and $\alpha < .5$ = Unacceptable. Following these rules, the actual Chronbach's alpha for the five dimensions of the SF-36 ranges somewhere between good and excellent. The highest Chronbach's alpha was found for role emotional functioning ($\alpha = .947$), followed by role physical functioning ($\alpha = .937$), physical functioning ($\alpha = .908$), social functioning ($\alpha = .845$) and finally mental health ($\alpha = .800$). Because the internal consistency turned out to be satisfying for all scales of the SF-36 that were used in this study, the SF-36 questionnaire turned out to be a reliable measurement tool for the current research purpose.

Table 2: Summary of Information about SF-36 Scales and Physical and Mental component Summary Measures

| | Items | SD | Reliability | Lowest Possible Score | Highest possible Score |
|-----------|-------|----|-------------|---|--|
| PF | 10 | 11 | .908 | Very limited in performing all physical activities, including bathing and dressing ^a | Performs all types of physical activities including the most vigorous without problems |
| RP | 4 | 11 | .937 | Problems with work or other daily activities as a result of physical health | No problems with work or other daily activities |
| | | | | Extreme and | Performs normal |

| | | | | | |
|-----------|---|----|------|--|--|
| SF | 2 | 11 | .845 | frequent interference with normal social activities due to physical and emotional problems | social activities without interference due to physical or emotional problems |
| RE | 3 | 13 | .947 | Problems with work or other daily activities as a result of emotional problems | No problems with work or other daily activities |
| MH | 5 | 10 | .800 | Feelings of nervousness and depression very often | Feels peaceful, happy, and calm most of the time |

^a From “SF36: Physical and Mental Summary Scales: A User's Manual”, by Ware, Kosinski & Keller

(1994).

Table 2 offers an overview about some characteristics of the SF-36 questionnaire, including a description of the meaning of high and low scores for each scale.

The 3-point physical functioning scale, which serves as control variable in the current study, consists of 10 items that measure limitation in physical activities as a consequence of health problems. Possible answer options for items of this scale range from “serious impaired” to “slightly impaired” until “not at all impaired”. In line with this, lower scores on this scale indicate impaired physical functioning, while high scores signal good functioning in the physical realm.

The 5-point social functioning scale contains two items that assess the extent to which patients are able to maintain social contacts and appointments. Lower scores on this scale indicate an impaired social functioning, while individuals with high scores are able to maintain social contacts and appointments without interference.

The 5-point role emotional scale consists of three items that assess limitations in the patients' usual roles because of emotional problems. The answer options range from "always impaired" to "never impaired". Thus, lower scores on this scale suggest impaired daily functioning as a consequence of emotional problems, while higher scores indicate the absence of impairments.

The 5-point mental health scale is made of five items that measure psychological distress and general mental health as experienced by RA patients. Answer options of items vary from "always" affected by negative feelings to "never" bothered by these feelings. Thus, lower scores on this scale indicate decreased mental health of patients.

In addition, the 5-point role physical scale includes four items that assess the extent of impairments in the fulfilment of daily roles because of physical restrictions. Response options range from "always" impaired in daily roles as a consequence of physical health to "never" impaired. Thus, lower scores on this scale indicate worse functioning, while higher scores suggest minimal disruptions in daily roles.

The SF-36 scale scores were constructed using the method of summated ratings based on several assumptions. First, items were constructed that all share roughly equal means and standard deviations. Using a scoring utility software, all eight health domain scales are standardized according to general population based norms (Mean=50; SD=10). Thus, each scale is supposed to have the same mean (50) and the same standard deviation (10), which makes it easy to recognize how far a score in a standardized unit deviates from the general population mean. Each time a scale score is below 50, health status is below the average of the general population (Ware, 2000).

Furthermore, equally representative items were selected, thus those items that have a roughly equivalent relationship to their underlying scale. In line with this, all items correlate substantially (greater than .40) with their associated scale dimension, with few exceptions (Ware, 2000).

All questions are scored on a scale from 0 to 100, while 100 represent the highest level of functioning that is possible. Accumulated scores are assembled as a percentage of the total scores possible. For this purpose, the RAND scoring table is used (see Appendix B, Step 1 Chart). The scores from the questions that address each specific dimension of physical or psychological functioning are averaged together and divided by the total number of answered questions in order to calculate a final score for each dimension (see Appendix B, Step 2 Chart).

For example, to assess the social functioning of a patient, one adds the scores from the questions 20 and 32 and uses the step 1 chart to score them. The value of the answered questions is then divided by to the number of answered questions (2 in this example) in order to get a total score. Since a score of 100 represents no impairments in social functioning, lower scores indicate that the patient is experiencing some limitations ("How to score the Rand SF-36 questionnaire").

An advantage of this approach is that general population norms make meaningful comparison across health domain scales quite easy (Ware et al., 2007). In addition, differences in scale scores clearly display disease impact so that health professionals can quicker and more effective interpret disease effects and treatment outcomes (Ware et al., 2007).

4.5 Pain

A single numerical pain scale assessed the amount of pain that emerged as a consequence of the disease over the past weeks. The participants were asked to select a number between 0 (no pain at all) and 10 (intolerable pain) that best suit their actual condition.

4.6 Analysis

The current research revolves around the general question “is there are a negative relationship between fatigue and quality of life in patients with musculoskeletal diseases?” More specifically, the current research aims at studying the relationship between fatigue and four separate dimensions of quality of life while controlling for possible intervening effects of physical functioning and bodily pain.

Data will be analysed using SPSS version 16.0.

A multiple, bloc wise regression analyse is used to estimate the relationship between one of the four dependent variables (RP, SF, RE & MH) and several independent variables (pain, physical functioning and fatigue).

A requirement for the use of a regression analysis is that one operates with interval scales. In addition, a regression analysis calls for a linear relationship between the variables. Thus, the relationship between the independent and dependent variable must be expressed in the form of a straight line (Huizingh, 2008).

In order to test if there exists in fact a linear relationship between the variables, one should make use of scatter plot graphs that confirmed that it is reasonable to assume a linear relationship between variables in the current study.

In order to test for a normal distribution of the variables, it is necessary use the Kolmogorov-Smirnov test. For this study, it turned out that all three measures of fatigue as well as physical functioning constituted a normal distribution. In contrast, pain scores and the remaining items of the SF36 (RP, SF, RE & MH) were not normally distributed.

With the objective of getting an impression of the degree and direction of the relationship between the dependent and independent variables, Spearman's correlation coefficient was used because the majority of constructs used in the study turned out to be not normal distributed. Altogether, all factors were correlated among each other. Values range from +1 to -1 and, whereby +1 constitutes a perfect positive linear relationship and a value of -1 indicates that there is a perfect linear negative relationship. In the case of the current study, correlations of $r \geq 0.6$ are referred to as strong, $r < 0.6$ to $r \geq 0.3$ as moderate, and $r < 0.3$ as weak.

In the next step a block by block regression analysis was conducted in which physical functioning and pain served as independent variables in a first bloc. In a second bloc, fatigue was added so that pain, physical functioning and fatigue together operated as independent variables. In each bloc, four separate tests were carried out in which one of the four dimensions of quality of life operated as dependent variable.

The dimension of fatigue effect was omitted in the regression analysis because through calculating Spearman's correlation coefficient it turned out that fatigue severity and fatigue effect correlate so strong with each other that one can conclude that the two dimensions of fatigue measure more or less the same underlying concept. Fatigue severity was chosen over fatigue effect because severity, like the pain scale, asks about the degree of symptoms while a measure of fatigue effect is likely to include several concepts (severity and consequences).

The Beta values of the regression analysis output show for each variable the strength of the relationship between the dependent variable, including the statistical significance. Beta values are standardized coefficients that can be directly compared among each other.

The R^2 values indicate how much of the variance of the dependent variable can be explained through the present independent variables.

To find out if the dimensions fatigue severity and fatigue coping add any explanatory value to the understanding of disease related physical and psychological complains, the values of R^2 change must be reviewed and tested for significance. The F change values test whether the complete model is significantly more successful in explaining the variance of QOL than the reduced model.

In this way, the effects of pain and PF were controlled and the unique explanatory power of fatigue could be recognized.

5. Results

The focus of interest in the current study was the question whether fatigue interferes with the quality of life of patients with musculoskeletal diseases. More specific, the aim was to test whether there exists a negative relationship between fatigue and the four dimensions of disease related quality of life (RP, SF, RE & MH) while controlling for pain and PF.

5.1 Correlations among the concepts

In order to get a first impression of the degree and direction of the relationship between fatigue, pain, physical functioning and the four independent variables (RP, SF, RE & MH), Spearman's correlation coefficient was calculated. Altogether, all factors were correlated among each other.

Table 3: Correlation coefficient between physical and mental health (SF -36) and fatigue, pain and physical functioning (N=207)

| | Fatigue Severity | Fatigue Effect | Fatigue Coping | Pain | PF | MH | RP | SF | RE | Mean | SD |
|----------------|---------------------|-------------------|-------------------|-------|-------|-------|-------|-------|-------|------|----|
| Fatigue | | | | | | | | | | | |
| Severity | | .77* | -.35* | .53* | -.30* | -.37* | -.45* | -.44* | -.31* | 49 | 25 |
| Effect | | | -.34* | .56* | -.35* | -.46* | -.51* | -.49* | -.36 | 49 | 29 |
| Coping | | | | -.34* | .23* | -.37* | .36* | .33* | .39* | 61 | 25 |
| Pain | | | | | -.36* | -.38* | -.54* | -.51* | -.36* | 5 | 3 |
| PF | | | | | | .34* | .61* | .43* | .34* | 38 | 11 |
| MH | | | | | | | .52* | .58* | .54* | 49 | 10 |
| RP | | | | | | | | .66* | .60* | 36 | 10 |
| SF | | | | | | | | | .56* | 43 | 11 |
| RE | | | | | | | | | | 39 | 13 |

* $p < .01$.

Table 3 indicates that most correlations between the variables are moderate strong.

The most outstanding exception is that fatigue severity and fatigue effect correlate very strong with each other ($r=.77$). Thus, fatigue severity and fatigue effect seem to measure more or less the same underlying construct. Fatigue coping scores correlated only moderately with fatigue severity and fatigue effect, which indicates that fatigue coping is associated with but does not directly measure the degree of disease related impairments.

In addition, pain together with fatigue severity and effect compose noticeable correlations. Thus, there seems to be a considerable amount of overlap between these independent variables.

There are two further exceptions from the remaining moderate correlations: fatigue coping and physical functioning constitute a surprising weak relationship with each other. Thus, counter intuitive, more effective fatigue coping is only weakly correlated with the physical functioning of patients, nevertheless the relationship remains significant. On the basis of current literature, it is likewise quite surprising that fatigue coping and mental health correlate only moderate strong with each other.

An additional striking exclusion is the strong positive correlation between physical functioning and role physical functioning, meaning that higher amounts of physical functioning are associated with higher degrees of role physical functioning. In addition, role physical functioning constitutes a relatively strong negative correlation with pain and mental health.

For social functioning, a strong positive correlation with pain, role physical functioning and mental health additionally catches the attention.

Likewise, role emotional functioning is especially strong correlated with role physical functioning and to a slightly lesser extent with mental health and social functioning.

Thus, it became apparent that the four constructs of the SF-36 that serve as indicators for physical and psychological functioning are relatively strong correlated among each other.

5.2 Explanatory power of fatigue

Four separate regression analysis were conducted for each dependent variable (RP, SF, RE & MH). In each case, in the first step physical functioning and pain served as independent variables. In the second step, fatigue was added so that physical functioning, pain and fatigue together operated as independent variables.

Table 4: Summary of Hierarchical Regression Analysis for Variables predicting role physical functioning (N=207)

| | B | SE B | β |
|------------------|--------|-------|---------|
| Step 1 | | | |
| Pain | .26.08 | 2.744 | -.363** |
| PF | .449 | .056 | .477** |
| Step 2 | | | |
| Pain | -.940 | .252 | -.244** |
| PF | .417 | .054 | .443** |
| Fatigue Severity | -.064 | .028 | -.149* |
| Fatigue Coping | .066 | .027 | .146* |

Note. $R^2 = .477$ for Step 1; $\Delta R^2 = .042$ for Step 2.

ΔF for model 1 = 77.541**; ΔF for model 2 = 7.266**

* $p < .05$. ** $p < .01$.

As table 4 indicates, physical functioning and pain significantly predicted role physical functioning both in step 1 and step 2 of the regression analysis. In line with this finding, a significant proportion of 47.7 % of all variance in role physical functioning was explained due to physical functioning and pain.

When fatigue severity and coping were added in a second step, the explained variance of all independent factors for role physical functioning rise up with 4.2 %. This increase seems not too large compared to the explanatory

power of pain and physical functioning. Nevertheless, both fatigue severity and fatigue coping are statistical significant at the $p < .05$ level in step 2.

Table 5: Summary of Hierarchical Regression Analysis for Variables predicting social functioning (N=207)

| | B | SE B | β |
|----------------------|--------|------|---------|
| <u>Step 1</u> | | | |
| Pain | -1.637 | .267 | -.406** |
| PF | .299 | .065 | .303** |
| <u>Step 2</u> | | | |
| Pain | -1.109 | .297 | -.275** |
| PF | .258 | .064 | .262** |
| Fatigue Severity | -.110 | .033 | .244** |
| Fatigue Coping | .025 | .031 | .054 |

Note. $R^2 = .340$ for Step 1; $\Delta R^2 = .050$ for Step 2.

ΔF for model 1 = 43.870**; ΔF for model 2 = 6.853**

* $p < .05$. ** $p < .01$.

For social functioning, table 5 presents a quite surprising finding: while PF and pain reach statistical significance both in step 1 and in step 2, only one dimension of fatigue (in this case fatigue severity) achieve statistical significance in the second step, while fatigue coping is not statistical significant. Physical functioning and pain explain comparably less variance in social functioning than in role physical functioning. Anyhow, round 34 % of the variance in social functioning is explained due to pain and physical functioning. In addition, the magnitude of explained variance increases with 5.0 % when fatigue severity and fatigue coping were added.

Table 6: Summary of Hierarchical Regression Analysis for Variables predicting role - emotional functioning (N=207)

| | B | SE B | β |
|----------------------|--------|------|---------|
| <u>Step 1</u> | | | |
| Pain | -1.411 | .358 | -.289** |
| PF | .290 | .088 | -.243** |
| <u>Step 2</u> | | | |
| Pain | -.758 | .393 | -.155 |
| PF | .249 | .085 | .209* |
| Fatigue Severity | -.040 | .044 | -.073 |
| Fatigue Coping | .164 | .041 | .289** |

Note. $R^2 = .190$ for Step 1; $\Delta R^2 = .082$ for Step 2.

ΔF for model 1 = 19.966**; ΔF for model 2 = 15.740**

* $p < .05$. ** $p < .01$.

Table 6 indicates that only physical functioning remains significant in all conditions. In line with this, fatigue coping reached statistical significance in the second step, while both fatigue severity and pain become statistic insignificant. Allover, a relatively slight proportion of variance in role emotional functioning is explained due to pain and physical functioning (19 %). Explained variance increased with a value of 8.2 % when fatigue severity and fatigue coping were added. This constitutes the strongest increase in explanatory power due to fatigue across all four health related dimensions used the actual study.

Table 7: Summary of Hierarchical Regression Analysis for Variables predicting mental health (N=207)

| | B | SE B | β |
|----------------------|--------|------|---------|
| <u>Step 1</u> | | | |
| Pain | -1.141 | .280 | -.301** |
| PF | .198 | .068 | .215* |
| <u>Step 2</u> | | | |
| Pain | -.554 | .311 | -.146 |
| PF | .154 | .067 | .167* |
| Fatigue Severity | -.083 | .034 | -.195* |
| Fatigue Coping | .080 | .033 | .183* |

Note. $R^2 = .182$ for Step 1; $\Delta R^2 = .068$ for Step 2.

ΔF for model 1 = 19.083**; ΔF for model 2 = 7.610**

* $p < .05$. ** $p < .01$.

Table 7 offers another surprising result: while both physical functioning and fatigue severity and coping significantly predicted mental health scores in step 1 and 2, pain did not reach statistical significance in the second step. In addition, the explained variance of physical functioning and pain is with 18.2 % relatively small. When fatigue severity and coping were added in the second step, 6.8 % of all variance in mental health is additionally explained due to the independent variables.

Altogether it became apparent that for mental health, social and role emotional functioning either fatigue severity, fatigue coping or pain reached statistical significance in the second step of the regression analysis, while under no circumstances all variables were simultaneously statistical significant. An exception is provided by the role physical functioning scale in which all independent factors remained significant both in step 1 and step 2.

In general, the explained variance of fatigue in comparison to pain and physical functioning seems to be relatively small. To the same degree that the explained variance of physical functioning and pain increased, the apparently explained variance of fatigue severity and coping decreased. Nevertheless, the F change values indicate that each predictor that is added to the model is significant for an explanation of health related quality of life. What further catches attention is the fact that a very high amount of role physical functioning is explained due to the independent factors, while the explained variance of role emotional and mental health is relatively small. For social functioning, a moderate amount of variance is explained due to the independent factors.

6. Discussion

6.1 Findings – Methodological reasons

The present study had the aim to answer the question whether fatigue influences the quality of life of patients with musculoskeletal diseases. In particular, I wanted to find answers to the question whether fatigue impairs the four dimensions of health related quality of life as measured by the SF-36 questionnaire while controlling for the effects of pain and physical functioning. On the basis of recent literature, my assumption was that heightened levels of fatigue will lead to decreased role, social and psychological functioning.

In line with present literature, the current research indicates that fatigue severity and fatigue coping explained between 4.2% and 8.2% of the variance in the different dimensions of health related quality of life of patients with musculoskeletal diseases. While the explanatory contributions of fatigue seem to be minor compared to the effects of pain and physical functioning, one must keep in mind that there is a quite high correlation between fatigue severity, fatigue effect and the other two independent variables (pain, physical functioning). Thus, the symptoms of pain, impaired physical functioning and fatigue often appear simultaneously. Especially, the correlation between fatigue and pain is relatively pronounced. This circumstance makes it fairly difficult to extract the unique explanatory power of each dimension when all independent variables are held constant.

The relatively high correlations among the independent variables is probably the cause for the effect that in the regression analysis of social functioning, mental health and role emotional functioning either fatigue severity, fatigue coping or pain reaches statistical significance, while under no circumstances were all variables simultaneously statistically significant. When all predictors of health related quality of life are held constant, the highly correlated independent variables enter into a kind of “struggle for statistical significance” where necessarily one factor wins out while the remaining factors subordinate themselves. Nevertheless, the adding of all predictors to the model (F change) was still significant. This fact indicates that all used independent variables are important for an understanding of health related quality of life in RA patients. Merely for the dimension of role physical functioning remained all independent factors in both steps of the regression analysis statistically significant. This finding might be explained due to the fact that in general the independent factors explained most variance for role physical functioning compared to the other three dependent variables.

6.1.2 Findings - Content reasons

In addition to methodological reasons, there might also be content reasons why the explanatory power of fatigue seems rather marginal compared to pain. The symptoms of fatigue might be to a lesser extent in the awareness of patients with musculoskeletal diseases because pain and not fatigue is the dominant topic in the media, in the literature and during medical consultations. Furthermore, the attribution of the causes of fatigue might not be clear to patients. Thus, it is possible that patients ascribe fatigue not to their musculoskeletal disease, but to other circumstances in their lives. In addition, as a general measurement of health related quality of life, the formulations of the SF-36 do not trigger fatigue symptoms very well. The majority of questions in the SF-36 ask about impairments as a consequence of physical health and / or emotional problems. If patients classify fatigue in none of these categories, the influence of fatigue on patients' health related quality of life will not be reflected in their answers.

An additional topic that is worth to consider is the fact that we do not know how severe the diseases of the participants in the actual sample really were. An additional possibility is that the majority of patients in the actual sample did not experience high baseline levels of fatigue. While not all arthritis patients complain about symptoms of fatigue, a sample with relatively low levels of fatigue could account for the finding that the explanatory contributions of fatigue seem relatively small. This assumption is confirmed by the fact that the majority of the actual sample consists of patients with relative short disease duration. 59.2 % of all participants are less than ten years diseased. As already mentioned, disease related complains typically decrease through the initial benefits of treatment in the first years after disease beginning and gradually rise in the successive years (Pollard et al., 2005). Thus, it is possible that the majority of the current sample shows early forms of RA and still benefits from treatment which will reduce the amount of fatigue that is experienced.

In addition, the refusal of patients to participate in the study might be a consequence of their higher levels of fatigue. Those participants that suffer from high amounts of fatigue are especially likely of being too tired to concentrate long enough to fill out the questionnaires on a computer screen. In this case, the relationship between fatigue and quality of life might be underrated.

Furthermore, while RA patients constitute around the half of the actual sample, we operated with a divided group of patients with altogether 12 different diagnoses. Nevertheless, the relationship between fatigue and quality of life in diseases besides RA remains unknown. It is possible that the presumed relationship has no validity for other forms of musculoskeletal diseases. If this possibility would turn out to be right, our findings would greatly underestimate the relationship between fatigue and quality of life in RA patients as a result of the divided sample.

Overall, although the explanatory contributions of fatigue seemed not too large compared to the effects of pain and physical functioning, the assumptions that fatigue would negatively influence physical and psychological functioning in patients with musculoskeletal diseases were met.

6.1.3 Fatigue coping

Surprising was the finding that coping with fatigue and mental health correlate only moderately strong with each other because former studies indicated that depression in RA patients is strongly associated with high use denial and low use of active coping, planning and the seeking of social support. Illness perceptions along with coping are generally thought to have a considerable influence on illness adaptation and disease status (Pollard et al., 2005).

Likewise initially unexpected was the finding that fatigue coping and the level of physical impairments were relatively weak correlated. Previous research showed that individuals who believed that their illness is a severe condition over which they have little control, who saw little hope for effective treatment and who coped with their illness in a passive way, reported decreased levels of physical and social functioning and greater problems with their mental health (Heijmansa, 1998). However, these results were mainly affirmed for psychosomatic diseases. It is very likely that coping styles differentiate between diverging diagnoses as well as between different symptoms of one disease. For example, for a range of symptoms that are open to improvement, a problem focused coping strategy might be most beneficial. Forms of problem focused coping might include active coping, planning, suppression of competing activities and looking for instrumental social support. In contrast, if the severity of the symptoms cannot be changed per se, it might be more adaptive to make use of forms of emotional coping. This might include the seeking of emotional social support, positive reinterpretation of events, acceptance, denial or one turns to religion as a source of internal strength. While passive coping is one of the most telling predictors of pain (Keefe, Brown, Wallstein & Caldwell, 1989), less literature is available about the impact of fatigue coping on patients' quality of life. Coping styles with regard to fatigue might be striking different compared to pain related coping styles. Because it is known that fatigue severity per se can often not be changed with current available treatment options, forms of emotional coping might be especially effective in order to change the meaning of the symptom and so reduce its impact (Nickelin, 2010).

In the actual study, fatigue coping is only moderate associated with the four dimensions of health related quality of life. But because the concept of coping is so multisided and complex we do not know which forms coping styles are caught through the used concept which is very broadly referred to as "fatigue coping". More specialization with regard to different coping styles in chronic diseases would be desirable. On open question that remains to be answered is: which forms of coping are dominant in RA patients dealing with fatigue? Further, which forms of coping are most successful in increasing the quality of life in those patients?

It turns out that more established knowledge is needed about various forms of coping throughout different diseases and for different symptoms. Thus, forms of coping and their related impact on quality of life in various forms of chronic diseases might be an interesting field of future research.

6.1.4 Social functioning

The comparable strong positive correlation between the extent to which patients are able to maintain social contacts and mental health is relatively easy to explain. It is reasonable to assume that diminished social functioning is negatively associated with mental health because previous studies indicated that there exists a causal relationship between the character of social contacts and health. It was shown that people with a decreased quantity and quality of social contacts are more likely to become ill, to suffer more and eventually die as a consequence of the disease (House, Landis & Umberson, 1988).

Social functioning correlates relatively strong with pain, role emotional and role physical functioning. This seems comprehensible because social support has been found to reduce the overall effects of physical limitations (Doeglas et al., 1994).

6.2 Limitations of the study

The results of the actual study should be viewed in the light of certain limitations.

First of all, although the SF-36 shows evidence of validation for the assessment of RA fatigue, even this scale would benefit from future research, especially with respect to content validity for RA patients, the inclusion of cognitive items and regarding the scales responsiveness to changes in the health status (Hewlett et al., 2007). In addition, the relatively high correlation between the four dimensions of quality of life as assessed by the SF-36 indicates that the dimensions may not differentiate enough between the different constructs that are measured.

It also makes sense to question the quality of life concept used in the actual study. The SF-36 envisages that physical functioning along with role-physical, social, role-emotional functioning and mental health constitutes the health related quality of life of patients. However, in case of the actual study, physical functioning serves as independent control variable and is excluded from the quality of life concept. Thus, it is a problem of the actual study that a measurement instrument is used that includes all concepts (both independent predictor variables and indicators of quality of life) in one questionnaire.

Furthermore, because I did not conduct an experiment, it is not possible to conclude that the detected statistical relationships arise out of a causal link. I can only assume that the independent variables are the cause of the decline in patients' health related quality of life. Alternatively to the assumption that fatigue is the cause of impairments in quality of life, the direction might be the other way around. Thus, it may be likewise possible that social, role and psychological impairments lead to fatigue.

In addition, I cannot preclude that additional third variables influenced the results. Thus, it is likely that the four reviewed dimensions of quality of life were affected by factors that were not controlled in the actual study.

Finally, because we do not know which patients for what reasons refused to participate in the current study, our research findings might have limited generalizability.

6.3 Implications

In general, pain and fatigue should be treated as a unit in the assessment and the treatment of disease symptoms. This makes intuitively sense because both symptoms are relatively high correlated and often appear as an interrelated bundle of disease related discomfort. In line with this, fatigue is known to boost pain and disability (Hewlett et al., 2005). Thus, because the actual findings suggest that RA fatigue affects quality of life, an intervention that addresses fatigue impact should improve the wider well-being of patients.

Unfortunately, until now the treatment of RA is primarily focused on physical impairments and pain while the symptoms of fatigue are often neglected (Kosinski, 2002). It turned out that there is still much to improve in the contact between health professionals and patients as well as in the treatment of musculoskeletal diseases in general.

6.4 Treatment options

Typically, changes in the patients' mood and the perception of illness are among the best predictors of fatigue in RA patients. Knowledge about these facts could be used to identify individuals at risk who might especially benefit from extra attention of the medical professionals (Hewlett et al., 2008).

First of all, it is necessary that medical professionals discuss fatigue complaints and self-management strategies with affected individuals on a regular basis. Detailed consultations might contribute to the patients' experience that their concerns are taken seriously, foster their feelings of self-control and the confidence to be able to manage the disease. Additional, information in the form of adequate literature could be provided in order to help patients to better understand the causes, effects and the management possibilities of the disease.

Not at least because until now pharmacological interventions can reduce but not resolve fatigue, effective fatigue self-management turned out to be critical in order to address the complex, bidirectional pathways of clinical (disability, pain, inflammation) and psychosocial factors (mood, beliefs, behaviours and coping) of fatigue (Hewlett et al., 2011). Research findings indicate a possible disconnection between fatigue severity and the ability to cope with fatigue. An implication is that patients might be able to enhance their ability to cope with fatigue and so reduce its effect, even if fatigue severity per se cannot be modified (Nicklin et al., 2010).

These finding once again point to the importance of the concept of fatigue coping, its influence on patients' quality of life and the related need to gain further knowledge about different coping styles throughout various diseases and for different symptoms within a disease.

Hewlett et al. (2011) recently conducted an experiment in order to investigate the effect of group cognitive behavioural therapy (CBT) on fatigue self-management and quality of life in RA patients. It turned out that CBT participants reported less impact of fatigue compared to controls. More specific, perceived fatigue severity, coping, disability, depression, feelings of helplessness, self-efficacy and sleep were better for those individuals that joined CBT. Generally, CBT make use of cognitive reconstructing in order to break through cycles of

thoughts and feelings that may trigger certain kinds of maladaptive behaviours. Through using reflective questioning with regard to fatigue related thoughts, feelings and behaviours, participants are invited to work out the important links themselves. Self-efficacy and confidence in the patient's ability to improve the current situation are enhanced through the learning of primary self-management skills regarding problem solving, goal setting, self-monitoring of activity/rest and energy management. Through reviewing cognitive or behavioural goals, patients can learn to achieve cognitive and behavioural changes in order to improve their overall well-being (Hewlett et al., 2011).

A useful strategy to combat the negative effects of fatigue and to strengthen the awareness of positive side-effects might be to adapt one's expectations and goals to the personal possibilities (Nikolaus et al., 2010). Finding meaning in a negative stroke of fate probably contributes to better health and a more functional adaptation to the disease. Therefore, the positive aspects of the disease should be stressed. For the purpose to fight the negative emotions, it is critical that external demands are adapted in order to meet the person's current abilities and individual goal-setting. In line with this, it turned out that young women with multiple roles in daily living are especially prone to the negative influence of RA fatigue. This finding implies that negative emotions are likely to emerge when the own possibilities do not meet with the external demands of multiple responsibilities (Nikolaus et al., 2010).

The majority of patients intuitively handle a variety of self-management strategies in order to antagonize fatigue, including acceptance of the disease, developing positive attitudes toward it, using actions as rest and pacing and some decide to carry on their normal activities besides worsening of their condition afterwards (Hewlett et al., 2005). However, most patients are uncertain about how to best manage fatigue and many of them view fatigue as rather unmanageable and uncontrollable. Affected people often expressed little trust that professional treatment could help them. In line with that, most patients feel that they must manage fatigue alone. These expectations might explain why patients rarely seek help by medical professionals even though their self-management strategies are not always successful. Likewise, professional support is rarely offered to patients (Hewlett et al., 2005).

In addition, psychological interventions in general are a useful mean to help RA patients with psychological distress. Through the release of psychological distress, a reduction of fatigue symptoms is often achieved (Evers, Kraaimaat, Van de Riel & De Jong, 2002). Following the same mechanism, compared to factual writing, emotional disclosure in the form of daily diaries has been proven an effective instrument to combat fatigue (Danoff-Burg, Agee, Romanoff, Kremer & Strosberg, 2006).

Supplementary, levels of fatigue can be influenced due to nonsteroidal antiinflammatory drugs (Meinicke & Danneskiold-Samsoe, 1980), through behavioural agents (Cella et al, 2005) as well as through individual and group exercise (Neuberger et al., 1997). Testing for anaemia, thyroid dysfunction, diabetes and depression might be advisable if patients do not respond to traditional RA medication. Treatment of these medical conditions has been shown to decrease overall fatigue (Hewlett et al., 2008).

7. Conclusion

Although the results of the actual study should be viewed in the light of certain limitations, it is reasonable to assume that fatigue has an additional influence on the health related quality of life of patients with musculoskeletal diseases after controlling for pain and physical functioning. In line with previous literature, the actual study found that fatigue explained between 4.2% and 8.2% of patients' physical and psychological functioning. Even if the additional explanatory power of fatigue seems rather marginal when comparing it to the effects of pain and physical functioning, one must keep in mind that all symptoms form an interrelated bundle of disease related complains that is difficult to disentangle. In addition, patients might be more aware of the symptoms of pain and physical functioning, ascribe the causes of fatigue to other circumstances in their lives rather than their disease. Alternatively, the actual research sample might have a low baseline fatigue level and the potentially missing validity of the relationship between fatigue and quality of life for the other forms of musculoskeletal diseases in the sample might lead to an underestimation of the impact of fatigue.

We can summarize that fatigue is a severe, common and chronic symptom of musculoskeletal diseases that has a considerable impact on all aspects of life. At the same time, both patients and health care professionals still lack knowledge about how fatigue is best to manage with the result that the issue is often not discussed with patients.

Of crucial importance is it that health care professionals become aware of effective fatigue self-management strategies. As with pain, fatigue should be addressed routinely in the practice, rather than waiting before patients themselves raise the issue spontaneously during consultation. The combined treatment of pain, physical impairments and fatigue turns out to be the most promising option for the future treatment of musculoskeletal diseases.

However, before optimal treatment can be obtained, more information about the causes and the treatment of fatigue is needed in order to develop and further refine existing self-management strategies. Moreover, additional variables could be included in future research in order to further enhance the explained variance of health related quality of life and in turn be able to better to help patients with musculoskeletal diseases.

8. References

Arthritis research (n.d.). Retrieved April 18, 2011, from <http://www.webmd.com/osteoarthritis/guide/arthritis-basics>.

Blalock, S.J. & DeVellis (1992). Rheumatoid arthritis and depression: an overview. *Bulletin on the rheumatic Diseases*, 41, 6-8.

Brekke, M., Hjortdahl, P. & Kvien, T.K. (2001). Self-efficacy and health status in rheumatoid arthritis: a two year longitudinal observational study. *Rheumatology*, 4, 387-92.

Cella, D., Yount, S., Sorensen, M., Chartash, E., Sengupta, N. & Grober, J. (2005). Validation of the Functional Assessment of Chronic Illness Therapy Fatigue Scale relative to other instrumentation in patients with rheumatoid arthritis. *The Journal of Rheumatology*, 32, 811-819.

Danoff-Burg, S., Agee, J.D., Romanoff, N.R., Kremer, J.M. & Strosberg, J.M. (2006). Benefit finding and expressive writing in adults with lupus or rheumatoid arthritis. *Psychological Health*, 2, 651-5.

Doeglas, D., Suurmeijer, T., Krol, B., Sanderman, R., van Rijswijk, M., van de Lee-Uwen, M. (1994). Social support, social disability and psychological well-being in rheumatoid arthritis. *Arthritis Care & Research*, 7, 10-5.

Engelhardt, M. (2003). Epidemiology of osteoarthritis in Western Europe. *Deutsche Zeitschrift für Sportmedizin*, 6, 171-175.

Evers, A.W., Kraaimaat, F.W., Van de Riel, P.L. & De Jong, A.J. (2002). Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: a randomized controlled trial. *Pain*, 1-2, 141-53.

Fifield, J., McQuillan, J. & Tennen, H. (2001). History of affective disorder and the temporal trajectory of fatigue in rheumatoid arthritis. *Annals of Behavioral Medicine*, 1, 34-41.

Frank, R.G., Beck, N.C. & Parker, J.C. (1988). Depression in rheumatoid arthritis. *The Journal of Rheumatology*, 15, 920-5.

George, D. & Mallery, P. (2002). *Spss for Windows step by step: A simple guide and reference*. Boston: Allyn & Bacon.

Heijmansa, M.J.W.M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions. *Journal of Psychosomatic research*, 45, 39-51.

Hewlett, S., Ambler, N., Almeida, C., Cliss, A. Hammond, A., Kitchen, K., Knops, B., Pope, D., Spears, M., Swinkels, A. & Pollock, J. (2011). Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Annals of Rheumatic Diseases*, 70, 1060-1067.

Hewlett, S., Cockshott, Z., Byron, M., Kitchen, K., Tipler, S, Pope, D. & Hehir, M. (2005, October 5). Patient's perceptions of fatigue in rheumatoid arthritis: Overwhelming, uncontrollable, ignored [Electronic Version]. *Arthritis Care & Research*, 53, 697-702.

Hewlett, S., Hehir, M. & Kirwan, J.R. (2007). Measuring fatigue in Rheumatoid Arthritis. A Systematic Review of Scales in Use. *Arthritis & Rheumatism*, 57, 429-439.

Hewlett, S., Nicklin, J. & Treharne (2008). Fatigue in Musculoskeletal Conditions [Electronic Version]. *Reports on Rheumatic Disease Series*, 6, 1-16.

House, J.S., Landis, K.R. & Umberson, D. (1988). Social relationships and health. *Science*, 29, 540-545.

How to score the Rand SF-36 Questionnaire (n.d.). Retrieved May 15,2011, http://www.chiro.org/LINKS/OUTCOME/How_to_score_the_SF-36.pdf.

Huizingh, E. (2008). *Inleiding SPSS 16.0 voor Windows and Data Entry*. Amsterdam: Sdu Uitgevers.

Huyser, B.A., Parker, J.C., Thoreson, R., Smarr, K.L., Johnson, J.C. & Hoffmann, R. (1998). Predictors of subjective fatigue among individuals with rheumatoid arthritis. *Arthritis & Rheumatism*, 41, 2230-7.

Katz, P.P. & Yelin E.H. (1993). Prevalence and correlates of depressive symptoms among persons with rheumatoid arthritis. *The Journal of Rheumatology*, 20, 790-6.

Keefe, F.J., Brown, G.K., Wallstein, K.A. & Caldwell, D.S. (1989). Coping with rheumatoid arthritis pain: catastrophizing as a maladaptive strategy. *Pain*, 1, 51-56.

Kirwan, J.R. & Hewlett, S. (2007). Patient Perspective: Reasons and Methods for Measuring Fatigue in Rheumatoid Arthritis. *The Journal of Rheumatology*, 34, 34-5.

Kosinski. M., Kujawski, S.C., Martin, R., Wanke, L.A., Buatti. M.C., Ware, J.E. & Peretto, E.M. (2002). Health-Related Quality of Life in Early Rheumatoid Arthritis: Impact of Disease and Treatment Response. *American Journal of Managed Care*, 8, 231-240.

Lipsky, P.E. (1994). Rheumatoid arthritis. In: Isselbacher K.J., Braunwald, E., Wilson, J.D., Martin, J.B., Fauci, A.S., Kasper, D.L. (eds.). *Harrison's principles of internal medicine*. (pp. 1648-55). NY: McGraw-Hill.

Mancuso, C.A., Rincon, M., Sayles, W. & Paget, S.A.. (2006). Psychosocial variables and fatigue: a longitudinal study comparing individuals with rheumatoid arthritis and healthy controls. *The Journal of Rheumatology*, 8, 1496-502.

Meinicke, J. & Danneskiold-Samsoe, B. (1980). Diclofenac sodium (Voltaren) and ibuprofen in rheumatoid arthritis. A randomized double-blind study. *Scandinavian Journal of Rheumatology*, 35, 3-8.

Mental health: strengthening our response (2011). Retrieved June 22, 2011, from <http://www.who.int/mediacentre/factsheets/fs220/en/>.

Morris, R. & Chalder, T. (2002). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, 55, 305-308.

Neuberger, G.B., Press, A.N., Lindsley, H.B., Hinton, R., Cagle, P.E. & Carlson, K. et al. (1997). Effects of Exercise on fatigue, Aerobic Fitness, and Disease Activity Measures in Persons with Rheumatoid Arthritis. *Research in Nursing & Health*, 20, 195-204.

Nicklin, J., Cramp, F., Kirwan, J., Greenwood, R., Urban, M. & Hewlett, S. (2010). Measuring Fatigue in Rheumatoid Arthritis: A Cross-Sectional Study to Evaluate the Bristol Questionnaire, Visual Analog Scale, and Numerical Rating Scales. *Arthritis care & Research*, 11, 1559-1568.

Nikolaus, S., Bode, C., Taal, E. & Van de Laar, M.A.. F. J. (2010). New insights into the experience of fatigue among patients with rheumatoid arthritis: a qualitative study. *Annals of Rheumatic Diseases*, 69, 895-897.

Pollard, L. & Choy, E.H. & Scott, D.L. (2005). The consequences of rheumatoid arthritis: Quality of life measures in the individual patient [Electronic Version]. *Clinical and Experimental Rheumatoid arthritis*, 23, 43-52.

Repping-Wuts, H., Van Riel, P. & Van Achterberg, T. (2008). Fatigue in patients with rheumatoid arthritis: what is known and what is needed. *Rheumatology*, 48, 207-209.

Rupp, I., Boshuizen, H.C., Jacobi, C.E., Dinant, H.J. & Van de Bos, G.A.M. (2004). Impact of Fatigue on Health-Related Quality of Life in Rheumatoid Arthritis. *Arthritis & Rheumatism*, 51, 578-584.

Schanberg, L.E., Sandstrom, M.J. & Starr, K. (2000). The relationship of daily mood and stressful events to symptoms in juvenile rheumatic disease. *Arthritis Care & Research*, 1, 33-41.

Stone, A.A., Broderick, J.E., Porter, L.S. & Kaell, A.T. (1997). The experience of rheumatoid arthritis pain and fatigue: examining momentary reports and correlates over one week. *Arthritis Care & Research*, 3, 185-93.

Tack B. (1990). Fatigue in rheumatoid arthritis: conditions, strategies and consequences. *Arthritis Care & Research*, 3, 65-70.

Treharne, G.J., Lyons, A.C. & Hale, E.D. (2008). Predictors of fatigue over 1 year among people with rheumatoid arthritis. *Psychology, Health & Medicine*, 4, 494-504.

Ware, J. E. Jr., Kosinski, M., & Keller, S.D. (1994). SF36: Physical and Mental Summary Scales: A User's Manual. Boston: The Health Institute, New England Medical Center.

Ware, J.E. (2000). SF-36 Health Survey Update. *Spine*, 25, 3130-3139.

Ware J.E., Jr., Kosinski M., Bjorner J.B., Turner-Bowker, D.M., Gandek, B. & Maruish, M.E. (2007). Advantages of norm based scoring. *User's Manual for the SF-36v2TM Health Survey*, 2, 81-84. **Retrieved May 12, 2011, from [http://www.qualitymetric.com/Portals/0/Uploads/Documents/Public/Norm-based%20Scoring%20\(NBS\).pdf](http://www.qualitymetric.com/Portals/0/Uploads/Documents/Public/Norm-based%20Scoring%20(NBS).pdf)**

Uw Gezondheid en Welzijn

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

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

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

| | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Uitstekend | Zeer goed | Goed | Matig | Slecht |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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

| | | | | |
|------------------------------------|-----------------------------------|--|--------------------------------------|---------------------------------------|
| Veel beter nu dan een jaar geleden | Wat beter nu dan een jaar geleden | Ongeveer hetzelfde nu als een jaar geleden | Wat slechter nu dan een jaar geleden | Veel slechter nu dan een jaar geleden |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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

| | Ja, ernstig beperkt | Ja, een beetje beperkt | Nee, helemaal niet beperkt |
|---|----------------------------|------------------------------|----------------------------------|
| a <u>Forse inspanning</u> , zoals hardlopen, tillen van zware voorwerpen, een veeleisende sport beoefenen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| b <u>Matige inspanning</u> , zoals een tafel verplaatsen, stofzuigen, zwemmen of fietsen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| c Boodschappen tillen of dragen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| d <u>Een paar</u> trappen oplopen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| e <u>Eén</u> trap oplopen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| f Bukken, knielen of hurken | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| g <u>Meer dan een kilometer</u> lopen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| h <u>Een paar honderd meter</u> lopen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| i Ongeveer <u>honderd meter</u> lopen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| j Uzelf wassen of aankleden | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |

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

| | Altijd | Meestal | Soms | Zelden | Nooit |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| | ▼ | ▼ | ▼ | ▼ | ▼ |
| a U besteedde <u>minder tijd</u> aan werk of andere bezigheden..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b U heeft <u>minder bereikt</u> dan u zou willen..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c U was beperkt in het <u>soort</u> werk of andere bezigheden | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d U had <u>moeite</u> om uw werk of andere bezigheden uit te voeren (het kostte u bv. extra inspanning)..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

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

| | Altijd | Meestal | Soms | Zelden | Nooit |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| | ▼ | ▼ | ▼ | ▼ | ▼ |
| a U besteedde <u>minder tijd</u> aan werk of andere bezigheden | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b U heeft <u>minder bereikt</u> dan u zou willen | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c U deed uw werk of andere bezigheden niet zo <u>zorgvuldig als gewoonlijk</u> | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

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

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Helemaal niet | Enigszins | Nogal | Veel | Heel erg veel |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

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

| | | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Geen | Heel licht | Licht | Nogal | Ernstig | Heel ernstig |
| ▼ | ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ | <input type="checkbox"/> ₆ |

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

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Helemaal niet | Een klein beetje | Nogal | Veel | Heel erg veel |
| ▼ | ▼ | ▼ | ▼ | ▼ |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

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

| | Altijd ▼ | Meestal ▼ | Soms ▼ | Zelden ▼ | Nooit ▼ |
|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a Voelde u zich levenslustig? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b Was u erg zenuwachtig? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c Zat u zo in de put dat niets u kon opvrolijken? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d Voelde u zich rustig en tevreden? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| e Had u veel energie? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| f Voelde u zich somber en neerslachtig? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| g Voelde u zich uitgeput? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| h Voelde u zich gelukkig? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| i Voelde u zich moe? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

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

| Altijd ▼ | Meestal ▼ | Soms ▼ | Zelden ▼ | Nooit ▼ |
|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

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

| | Volko- men juist | Groten- deels juist | Weet ik niet | Groten- deels onjuist | Volko- men onjuist |
|---|----------------------------|----------------------------|----------------------------|-----------------------------|----------------------------|
| | ▼ | ▼ | ▼ | ▼ | ▼ |
| a Ik lijk wat gemakkelijker ziek te worden dan andere mensen..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b Ik ben even gezond als andere mensen die ik ken..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c Ik verwacht dat mijn gezondheid achteruit zal gaan | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d Mijn gezondheid is uitstekend | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

DANK U WEL VOOR HET BEANTWOORDEN VAN DEZE VRAGEN!

9.2 Appendix B: Scoring table SF36

Step1: Scoring questions

| QUESTION NUMBER | ORIGINAL RESPONSE | RECORDED VALUE |
|----------------------------|-------------------|----------------|
| 1, 2, 20 ,22, 34, 36 | 1 | 100 |
| | 2 | 75 |
| | 3 | 50 |
| | 4 | 25 |
| | 5 | 0 |
| 3,4,5,6,7,8,9,10, 11,12 | 1 | 0 |
| | 2 | 50 |
| | 3 | 100 |
| 13, 14, 15, 16, 17, 18, 19 | 1 | 0 |
| | 2 | 100 |
| 21, 23, 26, 27, 30 | 1 | 100 |
| | 2 | 80 |
| | 3 | 60 |
| | 4 | 40 |
| | 5 | 20 |
| | 6 | 0 |
| 24, 25, 28, 29, 31 | 1 | 0 |
| | 2 | 20 |
| | 3 | 40 |
| | 4 | 60 |

| | | |
|------------|---|-----|
| | 5 | 80 |
| | 6 | 100 |
| 32, 33, 35 | 1 | 0 |
| | 2 | 25 |
| | 3 | 50 |
| | 4 | 75 |
| | 5 | 100 |

Step 2: Averaging items to form 8 scales

| SCALE | NUMBER OF ITEMS | AFTER RECORDING AS PER TABLE 1, AVERAGE THE FOLLOWING ITEMS |
|--|-----------------|---|
| Physical functioning | 10 | 3,4,5,6,7,8,9,10,11,12 |
| Role limitations due to physical health | 4 | 13,14,14,16 |
| Role limitations due to emotional problems | 3 | 17, 18, 19 |
| Energy/ fatigue | 4 | 23, 27, 29, 31 |
| Mental health | 5 | 24, 25,26, 28, 30 |
| Social functioning | 2 | 20, 32 |
| Pain | 2 | 21, 22 |
| General health | 5 | 1, 33, 34, 35, 36 |

Note. From: http://www.chiro.org/LINKS/OUTCOME/How_to_score_the_SF-36.pdf.