

Experience of fatigue in osteoarthritis and the role of coping: a qualitative study

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ABSTRACT (english)

Introduction

Patients with osteoarthritis (OA) commonly experience fatigue as a symptom, next to the more common symptoms as pain. The focus of this study is to gain further insight in the experience of fatigue in OA, how people generally tend to cope with OA induced fatigue and what role focusing on positive aspects plays in this.

Methods

Participants were 13 OA patients, gathered via a regional general practitioner and from Medical Spectrum Twente, Enschede, The Netherlands. Semi-structured in-depth interviews were conducted using a bottom-up scheme, meaning that the patients' answers were summarised and categorised via a coding process.

Results

The analysed interviews showed a prime characteristic of interindividual variance regarding the impact and nature of fatigue induced by OA. Patients were found to use many different coping styles to manage the feelings accompanied with fatigue and fatigue itself. Patients stated to benefit from positivity (such as expressing emotion and thinking positively) and acceptance, through having a feeling of being able to cope in a better way with fatigue.

Conclusions

Results of the analyses point towards a very subjective nature of experienced fatigue in OA, which puts forth the advice of targeting the help at the subjective and personal situation of patients. It also seems crucial to put emphasis on the possibilities rather than on limitations of the patient, and offering patients ways to accept the condition better.

ABSTRACT (dutch)**Introductie**

Patiënten met artrose ervaren, naast het symptoom pijn, vermoeidheid veelal ook als symptoom. De focus van deze studie is verder inzicht te krijgen in de ervaring van vermoeidheid bij artrose en hoe artrosepatiënten over het algemeen geneigd zijn om te gaan met de vermoeidheid en alsmede wat voor een rol het richten op de positieve aspecten ervan speelt.

Methoden

Participanten waren artritispatiënten, geworven via een regionale huisarts en bij het Medisch Spectrum Twente, Enschede, Nederland. Semi-gestructureerde diepte interviews zijn afgenomen, met behulp van een bottom-up schema. Dit betekent dat de antwoorden van de patiënten eerst zijn samengevat en gecategoriseerd m.b.v. een coderingsproces.

Resultaten

De geanalyseerde interviews gaven een primair kenmerk van vooral interindividuele variantie aangaande de impact en de aard van de vermoeidheid veroorzaakt door artrose. Gevonden is, dat patiënten verschillende copingstijlen gebruiken om om te gaan met de vermoeidheid, alsmede met de gevoelens die ermee gepaard gaan. Patiënten stellen dat richten op positiviteit (uitdrukken van emoties en positief denken bijvoorbeeld) en de acceptatie van de aandoening helpen bij het omgaan hiermee.

Discussie

Resultaten van de analyses wijzen op een zeer subjectieve aard van de ervaren vermoeidheid bij artrose. Dit suggereert een advies om de specifieke hulp voor artritis te richten op de subjectieve en persoonlijke situatie van de patiënten. Het blijkt ook cruciaal te zijn om nadruk te leggen op de mogelijkheden in tegenstelling tot de beperkingen van de patiënt, en om manieren voor te leggen waarmee de aandoening beter geaccepteerd zou kunnen worden.

INTRODUCTION

Osteoarthritis is a chronic condition, which strikes numerous people nowadays. Osteoarthritis is the most common form of arthritis and comes with high physical, emotional, economical and social costs (Power, Badley, French, Wall & Hawker 2008). The prominent cause of the condition is natural aging, which normally entails a great period of work and natural stressing of the joints, resulting in stressed body joints. Osteoarthritis (referred to as OA) is a clinical syndrome primarily characterized by joint pain, which comes with limitation in many different degrees, dependent of several factors such as age, general health and lifestyle (Conaghan, 2008). OA is one of the foremost causes of pain worldwide today, featuring symptoms like joint pain, (morning)stiffness, loss of function and fatigue. As of late, it has been confirmed that fatigue (not to be thought of as neurotypical everyday drowsiness) is an extremely common symptom in OA (Lagace, Perruccio, DesMeules & Badley, 2003; Power, 2008) and is mediated by mood states (Zautra, Fasman, Parish & Davis, 2007). Overall, any joint in the human body is capable of developing OA but knees, hips and hands are the most affected areas which are struck. (Conaghan, 2008; Lagace et al., 2003).

Pain is stated to be the most frequent symptom and worst problem of OA (Conaghan, 2008; Stone, Broderick, Porter, Kaell, 1997). Many patients experience continuing and persistent pain, which is a difficult problem, since the pain is often of long duration and can be severe. It can affect every single aspect of one's daily life and the overall quality of life (Lagace et al., 2003).

Physical cause and background of OA

OA is a metabolically active, degenerative rheumatic condition, that is not yet curable. The condition involves all joint tissues, such as cartilage, bones and the structures connecting them, synovium (the membrane surrounding the articular cartilage) and muscles. The pathological changes in osteoarthritis are primarily the localized loss of cartilage because of a too unsuccessful rate of its repairing process, and the faulty remodelling of newly formed bone. This results in continuing damage to both the joints and the tissues that surround them. This failure is possible at different joint sites. This explains the great variability in individual presentation of the condition (Conaghan, 2008).

OA is not defined as a 'disease' or a specific condition that stems from only one specific cause. It is generally better to view it is a *common complex disorder* with multiple risk factors.

These factors can be split up into three broad groups:

- Genetic factors (for example, the heritability for knee, hip and hand joint complications are estimated at 40-60%, though responsible genes are fairly unknown);

- Constitutional factors (for example, high bone density (contrary to osteoporosis), aging and obesity);
- Factors that regard more specific, biomechanical factors (reduced muscle strength over time, joint laxity, joint flexibility) (Conaghan, 2008).

It is important to stress that the nature of the several risk factors are very broad and have high variability, since a highly joint-stressing lifestyle creates a greater chance of developing OA than less stressing ones. Even though several risk factors give a broad and rich overview of the pathogenesis of osteoarthritis, this also gives a complication because not every risk factor can be extrapolated to specific corresponding joint sites (Conaghan, 2008). Another difficulty exists. The incidence and prevalence of osteoarthritis is relatively hard to estimate, because the structural changes (often and usually defined as unusual changes in joints displayed through imaging techniques) do not specifically correspond with certain pathological symptoms (stiffness and joint pain) (Conaghan, 2008).

The symptom of fatigue in osteoarthritis

In 2003, Canadians suffering from OA have confirmed that fatigue was a very prominent symptom, but it can be postulated that today there is still little knowledge about the nature of the experience and how it differs from person to person (Power et al., 2008). For reliability's sake, it is important to stress that fatigue levels and typical symptoms have been reported as similar to those of patients with rheumatoid arthritis (RA), because of which RA research can be used to look at the subjective fatigue in OA. Because of this reason, this paper's perspective will be based upon this assumption (Wolfe et al., 1996; Wolfe, 1999; Wolfe & Skevington, 2000). Fatigue is generally put into words as the subjective experience of general exhaustion of oneself, or tiredness. It is often seen as a form of physical weakness, or a state of depleted physical energy (Power et al., 2008). Patients have described physical fatigue as strongly related to joint pain, pain in the back, legs and so forth, whilst mental fatigue is argued to be the emotion of '...coming up against a brick wall', 'weakness' and 'loss of energy' (Power et al., 2008). In addition, this typical fatigue involves serious signs of very poor concentration, (Wolfe, Hawley & Wilson, 1996), a very acute nature of the fatigue was found in studies regarding RA patients (which makes it rather unpredictable) (Hewlett et al., 2005), and a significant shortage in energy regeneration during a night of sleep (Power et al., 2008). Thus, this form of fatigue in OA is often spoken of as radically different from the daily 'sleepiness' an 'average' person feels from time to time (Wolfe, et al., 1996).

Two studies in particular also found important results regarding fatigue experience in both OA and RA. First in regards to OA, Power et al. (2008) have found several important concepts in the experience of fatigue in their qualitative study regarding OA. First of all, they have stated that

there's a distinction between mental and physical fatigue. A variety of factors were attributed to feeling fatigued, such as the weather (this could be because of a possible depressing character of it), medication ('makes you feel draggy'), and particularly negative mood states (or the absence of positive affect). All in all, this study showed that fatigue brings about a great impact on life with its many aspects, including social- and work life (friendships were noted to be influenced greatly as well, since visiting in evening hours occurs sporadically when confronted with such high levels of fatigue) (Power, 2008).

In the qualitative study of Nikolaus, Bode, Taal & van de Laar (2010) regarding RA, the following findings have been reported. Firstly, women have generally reported more negative feelings than men (men tend to balance the intensity and duration of daily tasks better in advance). This was especially so when women were found to have multiple roles in their daily lives (housewife, spouse, employee). It is argued, that people happen to get less roles bestowed upon them when aging naturally, and therefore older individuals with RA tend to feel less fatigued and emotionally better. Several distinctions between forms of fatigue have also been made, namely (1) physical and mental fatigue; (2) fatigue with or without joint pain; (3) fatigue with or without desire to go rest, and (4) dizziness. Furthermore, three major components of fatigue were found that are important to fatigue experience, which are (1) severity, (2) duration and (3) frequency (Nikolaus et al., 2010).

The role of affect and coping

It has been shown that depression or negative affect (NA) is a major predictor of pain in OA (Wolfe et al., 1996; Pollard, Choy, Gonzalez et al, 2006; Huyser, Parker, Thoreson, et al., 1998). Daily pain is also the key factor that is linearly related to daily fatigue (Wolfe et al., 1996). Moreover, patients who greatly experience fatigue have a three times higher chance of having to deal with significant depression or NA. These two concepts of NA and fatigue thus seem to be bi-directional (Zautra et al., 2007). Zautra et al. (2007) however revealed that positive affect (PA) plays a central role in restoration of energy, and overall entails patients feeling that they suffer less from pain and NA states. It has also been noted that several RA patients (prominently above 67 years) have found some positive aspects of their RA induced fatigue in terms of e.g. taking the time to plan their activities more careful (Nikolaus et al., 2010). Zautra et al (2007) noted that people seem to be less affected by daily fatigue when PA states are experienced more frequently. It is very possible that the amount of experienced fatigue is influenced in some way by the way patients tend to cope with their fatigue. Therefore some attention will be paid to this concept in the next section.

Coping has been defined as 'effort to reduce the negative impacts of stress on individual well-being'. (Lazarus & Folkman, 1984). The process of coping comprises three major factors:

the perception, appraisal and reaction to the situation. When the demands of the situation exceed the perceived coping resources of the person, stress occurs (Lazarus et al., 1984; Alswin, Levenson, Spiro, 1994). We speak of coping behaviour in cases of specific behaviour that attempts to meet the demands of a specific stressful situation. A personal coping style on the other hand, refers to the general tendency of a person to deal with adaptation-demanding situations (therefore coping styles show structural personal characteristics). Also, a distinction is often made in coping literature between passive versus active coping, and problem- versus emotion-focused coping. In active coping, a person actively tries to change the situation in some positive manner to lessen the impact of the stressor (in case of this focus, OA) both mentally and possibly physically. This form is preferred to passive coping, in which case the person doesn't actively attempt to reduce the stressor's impact. In problem-centred coping, the stressor is tried to be changed in such a way that the person would feel emotionally better, for example by means of time management, communication with the social environment (spouse, friends), etcetera. Emotion-focused coping on the other hand focuses on expressing and regulating emotion. In general, effective coping behaviour comprises the concepts of acceptance, optimism, and expressing emotion, since these concepts altogether involve a focus on the positive aspects rather than the negative in evaluating oneself, the demanding situation and its stressor (Lazarus et al., 1984; Alswin et al., 1994; de Ridder & Schreurs, 1994)

People with such a coping style that focuses on the positive aspects of a condition generally seem to report less distress (de Ridder et al., 1994). In the Utrechtse Coping Lijst (Schreurs et al., 1993), several concepts are measured that focus on positive affect (emotion-centred), including (1) responding socially (seeking help and expressing emotion), (2) the absence of palliative reaction (avoiding), (3) thinking positively (finding good aspects of a problem), and (4) acceptance of the stressor. Responding socially would mean that the patient seeks help in his social bonds when pain, fatigue and possibly sorrow is experienced and being able to properly share their feelings with the other. Through this the negative emotions are relieved to some extent. When a palliative reaction occurs, the patient tries not to think about the condition and the consequences it entails and possibly tries to distract himself because of fear for their feelings. This is a passive form of coping, and when absent, more effective coping is possible. Thinking positively is the ability or tendency to focus on the positive sides or consequences more than on the negative ones; the patient would thus mention positive consequences of a stressor that asserts negative influence on the patient. Acceptance of the stressor (the OA condition), would imply a patient being able to fully accept the stressful situation they are in and not using a palliative form of coping. These emotion-focused concepts will be sought after in the coding process of the interviews conducted in this research, together with other problem-focused coping constructs that

are more physical and concrete of nature to compensate for the fatigue, such as resting, taking baths, doing exercises, time management and so forth.

In sum, this study evaluates the experience of fatigue in OA and the role of coping to deal with the fatigue (Zautra et al., 2007; de Ridder et al., 1993). Taken into account Zautra's results, coping styles that involve focus on positivity could influence the experience of fatigue in such a way, that it is experienced as less severe and has less negative impact on the patient. As noted in the section above, positivity-focused coping styles are for example: expressing emotions, positive thinking, the absence of palliative (or other passive) coping behaviour and acceptance of the stressor (Schreurs et al., 1993). All these constructs are associated with enough cognitive resources and motivation to engage in sorts of behaviour which likely resolve problematic situations. In terms of the condition of OA, this should be interpreted as the patient's focusing enough on the positive aspects of their own feelings and their appraisal of OA to be able to deal well enough with their fatigue.

In the framework of a bachelor thesis assignment, this paper focuses on how coping behaviour with an emphasis on positive coping-concepts can affect the subjective character of fatigue in OA. This research is done through semi-structured interviews, which focus on the aforementioned constructs (extracted from the Utrechtse Coping Lijst (Schreurs et al., 1993) and The Ways of Coping Checklist (Lazarus et al., 1984)) involving positivity in self- and situation appraisal. Because of the available time in this bachelor thesis framework, this research is unfortunately forced to be of a retrospective nature. An extensive look will be taken at (1) how the patients report their subjective experience of fatigue induced by OA. Furthermore, (2) how they cope with their fatigue and (3) how big the role of focusing on positivity is in this and how it effects the experience of fatigue.

METHODS

By confidential contact with a local general practitioner, Almelo, The Netherlands, and through the rheumatology clinic of Medical Spectrum Twente, Enschede, The Netherlands, several patients were invited to participate in this study. The patients were either contacted via e-mail or telephone and with interested patients an appointment was made. In most cases, the interviewer went to the home of the contacted patient.

Sample

The sample consisted of 13 patients, who were approached and agreed to participate in the study so there were no dropouts. One man and 12 women participated, with a mean age of 67 years

(SD=8.76). The range of age was from 58 years to 82 years. Duration of the OA in this sample ranged greatly, from 7 years to 30 years, with a mean of 16 years (SD=7.20). Fatigue reports also rather differed, ranging from a score of 2.5 to 8 on a 1 to 10 scale in the week before being interviewed (Mean=5.83; SD=2). All patients have children, most of which lived in another home than the patient. Some interesting characteristics concerning the sample: two of the patients still did normal paid work, whereas 6 did volunteer work; 4 took extensive care of pets and 4 loved gardening. Only 1 patient still did a course in dutch at a local school and 3 patients took care of others outside their own household. 10 patients are married, whereas 1 a widow, 1 is unwed and 1 is divorced. Some of the patients had a secondary diagnosis, such as diabetes mellitus, Schroder syndrome, and possible other joint syndromes. An informed consent was used to make certain the patients were consciously participating in the study (questions and informed consent are listed in the appendix).

Interviews

The interviewer used an hierarchical interview scheme, which includes several main topics and an number of subquestions. Main topics were 1.) General information regarding the patient (age, marital status, gender), 2.) A role analysis (Nikolaus et al. (2010) argued multiple roles could be related to higher levels of fatigue in RA), 3.) General information regarding the osteoarthritis, such as duration, severity and what general complaints are at hand, 4.) Experience of fatigue, 5.) Ways of coping. 6.) Additional comments. This interview scheme is based on previous interview studies (Nikolaus et al., 2010; Power et al., 2008) and questions in the fifth topic concerning coping and more specifically positivity-focused coping styles were extracted from the Utrechtse Coping Lijst (Schreurs et al., 1993) and The Ways of Coping Checklist (Lazarus et al., 1984). . The fifth section ended with a sub-focus on acceptance, asking more about patients' view on the role of acceptance of the condition and how this influences their experience of OA induced fatigue. A comprehensive question scheme of the interview can be found in Appendix I.

Interview topics

(1) Disease-related and personal situation	e.g. "Do you have children, and what are your daily activities?"
(2) OA-related specifics	e.g. "How severe is your fatigue in general, how long does it last and how frequent is it?"
(3) Experience of fatigue	e.g. "How would you describe your fatigue?"
(4) Coping with fatigue	e.g. "How do you deal with your fatigue?"
(5) Social environment	e.g. "What things do other people do to

	lessen your fatigue?"
(6) Affect and consequences	e.g. "What are your feelings about the fatigue and how does it influence fatigue?"
(7) Acceptance	e.g. "How do you see yourself in how well you accept your condition?"

Analyses

All semi-structured interviews were recorded on audiotape and afterwards transcribed verbatim. A mixed bottom-up and top-down coding scheme was used, comprising of only the main interview topics at first (top-down) and through axially coding new categorisations were made (bottom-up). The process of coding comprised of descriptively coding the verbatim interviews first, which resulted in three code schemes (fatigue experience, coping and positivity; see Appendix II). At this point, the schemes were axially coded, further categorising the schemes. Some new codes emerged during the coding process, so already analysed interviews were checked for these. At this point, an overview was made of many fatigue descriptions, the most common coping methods and the role of positivity and acceptance. The primary focus here lies on the quantity of certain codes appearing in the analyses, assuming for example when physical exercise emerges often, this is seen as an effective way of coping by the patients in this sample. Important here is to see what the patient's view is on the matters presented by the interviewer. All analysed interviews were checked by two researchers from The University of Twente, The Netherlands.

RESULTS

Experience of fatigue and prominent characteristics

Firstly, it became clear that every patient of this specific sample suffers from a form of fatigue induced by OA, as well as that patients experience fatigue in a variety of ways, such as feeling 'heavy', feeling more 'sluggish', breathless and that "you have to drag yourself through the day".

"Ehm, yeah.. My fatigue..., it is like you're having a really strong feeling of being heavy. That you are not even feeling like wanting to lift your legs up anymore, so.. very heavy arms and legs. Perhaps even like gravity is pulling you down too severely" (R1, woman, 59)

"My fatigue is really severe sometimes. Yeah phew, ehm.. You compare it to the fatigue you had in the past. It's like I have to listen to my body more nowadays in comparison to before" (R2, woman, 64)

"My fatigue is like.. well, how could I explain it to you.. It's like fatigue is showing its face much sooner, that your joints start to ache sooner too (...) It's like it is much harder to move yourself. Perhaps.. like you're dragging yourself through the day and you have to make every move more consciously" (R5, man, 60)

"At the moment I mostly suffer from severe shortness of breath (...) then you sit again, and fatigue goes away very quickly" (R9, woman, 81); ("It's constantly there, that fatigue.. When I wake up I already have it (...) and I've had it for years now" (R7, woman, 64).

According to the patients, fatigue seemed to be related to several factors that could form the subjective character of the patients' fatigue experience: pain, and mental activity and activity surrounding the patient.

"... yes, because pain and fatigue go hand in hand, there's no doubt about that. The more pain I feel, the more fatigued I feel as well. Doesn't that sound rather logical?" (R12, woman, 65)

"For example like it was this very morning.. I've had some help from the care center. Personally, I'm not doing very much, but the person is walking around you constantly and she's talking and going about.. And yes, sometimes I just nod off then. It's because of the all the thinking. All the mental 'stuff' going on" (R11, woman, 82).

Since there seems to be such a variety in ways patients experience of fatigue, it could be that it is not solely the fatigue that is experienced in these reports, but rather a mixture of more symptoms. It is likely other factors also contribute to the difference in these reports, for example the amount of sleep the patient has had, mood states, amount of activity, and so forth.

Another prominent finding is suddenly becoming very fatigued when activity is either in a form that is not performed very often (no routine-wise form), or incidental.

".. though, those are actions which are more routine and you do them daily. It is like your muscles are used to them and so activities are less straining (...) So as I said, it is less straining so you can do more without getting tired all of a sudden" (R5, woman, 60)

"For example, when I've been going to school do to do a course in dutch, I really shouldn't make any more appointments after that since I'm just totally wiped out then. It is quite the same when I come home from therapy too" (R12, woman, 65).

In accordance with the finding of Powers et al. (2008), the weather conditions seem to be of importance, since 'grey' and cold weather have a depressing influence and worsen fatigue and possibly pain.

"Hmm well, when it's cold, I can go lie down under a solarium, and after I've warmed up again I feel much better. I've had my share of rest then and I can go on. (...) And I'm also less fatigued when I'm warm too.. so yes, it's very dependent of the weather" (R12, woman, 65)

"So for example, when I go outside to walk about for a bit and the weather is sunny and nice, I feel much better (...) I mostly feel better in terms of feelings. But it makes me feel less tired in general I think you could say" (R13, woman, 64)

"Yes, I feel especially fatigued in the time of winter as opposed to the time of summer. And also especially when it's grey and dark outside.. It really matters I must say. On a winters day, ehm.. Yes, a winters day really influences my mood and my quality of life" (R4, woman, 59).

In fatigue duration (ranging from fifteen minutes to two whole days) and regaining strength/energy after having had a period of fatigue the following has been found. Patients seem to state that there is strong variance in the time needed to regain energy, ranging from a short period of rest (5 minutes) to not being able to recover totally in a day's time.

"The fatigue I feel is constant and I feel it throughout the entire day, I don't know anything different.." R7, woman, 64); ("And when I feel the shortness of breath, I just sit down for a moment and it passes again fairly soon.." (R9, woman, 82)

"Well, I still work at my age, and I have a rather hectic job. I work in the nursery of this neighbourhood, and ehh.. when I have worked for 4 days straight, I really need some days off to regain my strength" (R4, woman, 59)

"Well, when the fatigue comes on and starts to play a role, I have to sit down for a few moments.. but half of the times, I just stand up again and I haven't actually really recovered in that period of time, but I just keep going since you simply have to. And this fatigue lasts about 15 minutes, but yes.. this way it never really disappears but it stays bearable" (R3, woman, 72).

Coping with fatigue

Many patients seem to use different skills of coping simultaneously, but nonetheless very distinct coping styles have been categorised. First of all, consistency of the coping style varies from

patient to patient. It also seems, being able to cope with fatigue is dependent of the emotional well-being of the moment.

Interviewer: "So if I understand correctly, you don't deal with your fatigue in a different way from time to time?", Respondent: "No, there's no other way to deal with the fatigue really, I think. Yes sometimes, you share it more with the other person how fatigued you are, but no. I just sit in the chair and rest when I need to (...) There aren't many options to choose from now, are there?" (R10, woman, 82)

"I attack my fatigue differently dependent of my, ehm.. spiritual state, my sense of being satisfied. It really seems that how I deal with me being tired somehow connects with what my emotions are at that point and how good I feel" (R6, woman, 58).

Different forms of emotion-focused coping have been found, namely trying to establish a positive affect, ignoring fatigue, expressing emotion and putting fatigue into perspective. Firstly: trying to establish a positive affect:

"This last month I've been to a course, organised by the church and we had to paint certain icons from the bible and the crucifixion of Christ.. And I have to admit, it was actually really really tough, but in the end I look at the paintings and I feel that I've conquered my condition just a little bit. And I'm proud of myself that way! (...) And yes, it even makes me feel less tired this way" (R3, woman, 72);

Secondly, ignoring the fatigue is also used as a common coping strategy. It does seem that ignoring doesn't play a positive role in dealing with fatigue, so the absence of it seems more beneficial:

"Well, mostly, I just try to ignore my fatigue.. And I keep trying to do that, but yes, eventually it doesn't really work and get even more tired.. Then you think "Ahh, not anymore!" and I try to seek some relaxation" (R4, woman, 59)

"... so when you're doing something and it's fun, I try to keep having fun and so I kind of ignore the fatigue I'm feeling. I just don't want to surrender to it at that certain point and I push it away from me (...) But yes, I feel rather stiff when I've ignored it, because you went past your own limits" (R5, woman, 60).

Thirdly, expressing emotion towards social environment:

"Well, I think my partner experiences my fatigue the sooner than others. Because, when I'm really very tired I can sulk a bit from time to time, because ehm.. yeah, everything is just becoming too much then. It's just that, ehm.. you simply can't deal with too much then, so you can sulk and you feel a little bit relieved" (R4, woman, 59)

"So when I really can't go on any further, it's usually the person next to me that gets to deal with all my emotions.. and I just fall down on the couch and say 'no!' to what people demand of me. Just not at that moment. I need a little moment for myself then" (R5, woman, 60).

Lastly, putting fatigue into perspective:

".. and yes, at those points where you've been tired and annoyed because of it, I just think "that one also has a disease, and that person also suffers from a condition, and as long as I can cope, I'm fine right?". So yes, I don't really give it that much thought how fatigued I am, I just hope the complaints stay the same for as long as possible" (R4, woman, 59).

In problem-focused coping, patients have reported varying ways of dealing with OA. These are: staying fit through exercise, resting and proactive coping. The first prominent way is trying to stay fit through e.g. exercise and doing as much as possible:

"It's like I said, you have to adapt yourself to the activity that you're doing. That doesn't mean you should do very little with what you still can, it's just.. adapting. And if that doesn't work, you just do something else which asks less of your body" (R2, man, 60)

".. and how fatigued I'll be in the coming future? I don't try to worry that much. I do what I can do for as long as I'm able to do it, and I try to stay in motion. I also keep trying to participate in the activities I want to and until so far, I've managed to do that" (R4, woman, 59).

Secondly, resting is also a very common form of problem-focused coping:

"Oh yes, when I'm tired, I just sit on the couch for half an hour and after that I'm capable of going on for quite some time again. So just resting is really the best way for me to deal with fatigue" (R5, woman, 60)

"I tend to stay in bed for quite some time in the morning to rest properly (...) Yes, I can lie in bed all day for that matter. It's not really healthy perhaps, but sometimes my body tells me I just need it. And even then I can sleep the whole night" (R7, woman, 64)

Thirdly, proactive coping. This concept was found the most and consists of thinking consciously about what fatigue is to be expected during the day, and trying to find the best coping skill for that fatigue in advance. This is a form of accumulating your coping resources and preparing yourself for the stressful event that is certain or very likely to occur.

"So, since approximately halfway last month I've decided to be very clear in how far I can go: I'm going to do this and that, and nothing more!" (R4, woman, 59)

".. and ehm, sometimes that balance, that you need to maintain in order to stay energetic is disturbed by external factors. And ehm, when that happens, I have to 'press the brake' and really be clear in how far I can go with a certain activity in order to regain the balance I had" (R4, woman, 59)

".. it doesn't imply you shouldn't do certain things anymore, I mean.. I do what I can do, even when I know it can be tough. I try to be conscious of how much I could do, and I stop exactly! where I can't go any further" (R5, woman, 60).

Moreover, almost every patient states having a strong self-efficacy. They believe not letting yourself get restrained by challenges plays a positive role in coping with fatigue. It could likely best be viewed as resulting in positive affect and feeling proud of one's actions through not giving up. It is important to be noted here, that this differs from a form of acceptance since acceptance doesn't involve a sense of being able to tackle certain challenges. Acceptance has its emphasis on 'not distancing yourself from the stressor emotionally and deal with the stressor from that position'.

"... yes, it somehow just makes you less tired in your mind when you have a strong feeling of being able to deal with everything." (R11, woman, 28)

"I consider myself being very capable of dealing with the fatigue induced by my condition. I'm really honest with this and I dare to say it concretely. Like I said, when I'm tired, I can just drop all my activities and work. I'm not someone who's a perfectionist.." (R5, woman, 60).

Acceptance

In general, patients in this sample have stated that acceptance is very crucial in regards to coping with both arthritis in general and the fatigue it brings along.

"Well, I could say acceptance comes more and more over time (...) and you also start to feel better over time that way" (R6, woman, 58)

"Everything just seems harder then. It's more psychological this.. When accepting fails, then eh.. I feel nasty and just everything feels worse. I think I also get more pain in that state. It's really a psychological effect I believe, but it makes me feel my pain and fatigue not only in my fingers or that wrist, but in my whole body. So.. acceptance is important! Chin up!" (R3, woman, 72)

A clear distinction can be made between accepting ones condition and the absence of acceptance. Whereas a patient accepts his or her OA, the case is an active acceptance form, which brings about an attitude of trying to live with it through a sense of OA being a part of your life and trying to maintain a positive mood. This is exemplified by for example "Yes, accepting is not always easy, but rather crucial" (R8, woman, 64). Also, she states acceptance making coping with fatigue easier ("I really believe the more positive the person is in this, the better he/she can cope with fatigue (...) so what I'm saying here is that I think, how positive you are in your life and how you see your own disease, the less tired you are", R8, woman, 64).

No acceptance is said to give 'more pain in a mental way', 'giving a negative humour' and 'more pain in different locations' (R10, woman, 82). Also, one patient stated the easiness of accepting OA and fatigue is dependent of the "severity of pain, severity of fatigue and self-efficacy in my experience, but of course I could be wrong.. but that's my personal situation I guess, haha" (R12, woman, 65).

Furthermore, a clear distinction can be made regarding no acceptance. There seems to be a distinction where the patient shows a passive form which is characterised by an attitude of learned helplessness ('not caring anymore', 'not trying to improve the quality of life'). In this situation, the patient doesn't even make attempts to accept the stressor (OA). Another form, on the other hand, is in fact still trying to accept the stressor but the patient fails. Again, this failing is possibly due to the three mentioned factors (1) severity of pain, (2) severity of fatigue and (3) self-efficacy.

"Arthritis.. well yes, you have no choice but to live with it and deal with it. You can just try to do as much as possible. Because, for example, I've had a period of time, in which I didn't do much and just didn't accept my condition but.. just laid down and didn't do any activities. It's because you think you can't do anything about it and feel helpless. You have to keep going" (R7, woman, 64)

Affect

Analysed interviews have shown several effects of both negative affective states and positive affective states. First, NA states seem to worsen the feeling of being fatigued. It's also stated that it could make you more passive in coping with fatigue.

"Look, it's just that when there's something going and that's making you feel bad for some reason.. people shouldn't be nagging at you and you feel somewhat agitated. And so yes, you don't feel good, and even only that makes you feel more fatigued!" (R10, woman, 82)

"Negative emotions? Yes, I think they do indeed matter greatly. Ofcourse.. When you're feeling bad, you just sit down again and you don't really do much else. You simply sit.. You don't 'push yourself', so to speak" (R9, woman, 82).

In PA states, the following findings have been found: PA states in general seem to lessen the severity of fatigue. It also seems possible to make acceptance of and/or coping with the fatigue somewhat easier.

"Negative emotions don't play a very good role, haha. I can get somewhat sulky, a bit agitated.. But that only happens when I've gone behind my own border of activities, so I've done too much and thus I'm rather exhausted. But when I'm feeling good for some reason, I can admit my fatigue easier and accept it easier. You can expect the fatigue a bit easier" (R12, woman, 64)

"If you're having a good day? Yeah, I tend to walk about then and it's really easier to handle the fatigue you could be having. It doesn't really make me feel less fatigued. You still feel it.. But it's simply easier in general, you feel happier" (R9, woman, 82)

"The consequence of good feelings.. Yes, I tend to go out! When being very happy, ehm.. It seems to make your level of acceptance rise. It's easier to accept. It just goes more easily. That's just how it is. If you're not feeling well, you just say "No I don't want to" sooner, but when you're feeling good? You say "I want to do something fun!" and you accept your fatigue" (R8, woman, 64).

Miscellaneous

Nikolaus et al. (2010) have found the possibility of multiple roles filled by female RA patients to be linked with fatigue levels. Looking at reports of fatigue levels (in the week before the

interviews were conducted) in this study's OA sample, lower level fatigue reports don't seem to be linked to a low quantity of roles in younger women. Also, higher level fatigue reports don't seem to go hand in hand with a higher quantity of roles in younger women either. Due to a higher range of age in this study's sample, this matter could not have been studied properly.

Another crucial finding is the notion of many patients reporting a sense of social misunderstanding of their condition. This social misunderstanding is a subjective experience. Also, this sense is reported in regards to the informal social environment such as the partner and/or friends, but concerning the professional social environment as well.

"Like I said, people who don't understand me! It's like they move in a train which goes faster than my own, and I let them pass. And to be honest, that has been a rather negative experience for me (...) So yes, I have to let my friends know how I feel and that I sometimes simply can't go on. They think "What's wrong? I'm tired sometimes too and I get older as well" (R8, woman, 64)

"Who doesn't have arthritis and who hasn't felt pain before like me really just doesn't know what it is exactly. And I really think that's hard. People tend to know a lot about cancer for example, but if I ask my own environment, they don't really know what's wrong with me. Like arthritis isn't possible to capture into concrete images for them to understand" (R3, woman, 72)

DISCUSSION

In this study, the most prominent findings were the variance that exists in the description of fatigue experience in OA. Patients all seem to have a subjective connotation of the fatigue. Also, variance seems to exist in the way patients deal with the fatigue, whereas some focus more on the problem and others seem to focus more on processing of emotions. And in general, there seems to be consensus regarding the role of acceptance in a way that it positively influences coping with fatigue and making it more bearable.

Firstly, an extensive look has been taken at the subjective character of fatigue experienced by OA patients. Hewlett et al. (2005) and Nikolaus et al. (2010) had found many different descriptions of fatigue in RA patients. Also an acute nature of fatigue. Power et al. (2008) also found variance in OA patients describing their fatigue. This also seems to be the case in this study. This could be due to fatigue being related to different perceived causes and factors such as affective state, weather conditions, pain levels, the nature of the activity (common or uncommon) and duration. Furthermore, the distinction between mental and physical fatigue is also found in this study, which was already found by Nikolaus et al. (2010) in RA patients. Activity

surrounding the patient also seems to be of influence on fatigue experience. In sum, it seems the finding of interindividual variance is very prominent and is in accordance with previous research.

Secondly, coping styles were examined. In general, multiple forms of coping are used simultaneously. As found in previous studies of Power et al. (2008) and other OA studies (Lagace et al., 2003; Conaghan, 2008; Berg & Upchurch, 2007), problem-focused coping strategies such as resting, exercising and staying in shape are found again in this study. As for emotion-focused coping strategies, trying to maintain a positive affect, ignoring and expressing emotion are found. As for stress avoidance coping (ignoring), another coping study regarding chronic conditions in general also state that primarily the absence of avoidance strategies is crucial for an effective way of dealing with fatigue (Berg et al., 2007). This is in accordance with the findings of this study, since ignoring fatigue mostly seems to result in becoming even more tired. Next to these coping strategies, proactive coping is especially found in this sample of patients. Proactive coping comprises knowing well how much activity you can handle before fatigue and pain start to play a role. And also, it involves careful planning and being efficient in your actions. Looking at other related studies concerning proactive coping (Ouweland, de Ridder & Bensing, 2007) in fatigue that is rather independent of pain levels or other factors, a possible better term is sometimes noted, which is 'anticipatory coping'. This specific form of coping is generally described as 'involving preparation for the stressful event whose occurrence is highly likely, and coping resources aren't directed at a specific external stressor'. In other words, the form of the external stressor isn't tried to be altered and this could be a logical coping strategy for patients that suffer from constant fatigue (Ouweland et al., 2007). For example, in a study involving proactive coping in Chronic Fatigue Syndrome, a syndrome involving constant fatigue which is rather independent of activity, only anticipatory coping seems to be effective (Fry & Martin, 1996).

Lastly, a look was taken at the concept of positivity-focused constructs and acceptance. It was found in research of Wolfe et al. (1996) and Zautra et al. (2007) that NA is directly linked to pain levels, and this indirectly to fatigue. The same has been found in this study. NA states seem to worsen the sense of fatigue and pain, and on the other hand PA states gives a feeling of being able to cope better with fatigue and lessened levels of fatigue. Acceptance is easier when being in a positive mood, and harder when being in a negative mood, but in general it is stated acceptance can simplify and make coping with fatigue easier. This is also in accordance to the assumptions of Zautra's study (2007) and this study, which were that positivity-focused constructs (thinking positively, expressing emotion, acceptance of the condition) could play a role in better ways of coping with fatigue. It's not entirely clear how these factors can be constructed into a definitive model and how factors influence each other in different ways. Furthermore, in a related study concerning pain coping strategies in OA by Berg & Upchurch (2007), a scale called 'Rational Thinking' was used, where high scores were related to better health status and less psychological distress. High scores on the scale were associated with better health status. This scale was

described as 'consciously being aware the condition is part of your life'. This scale is similar to the construct of acceptance found in this study and a similar effect is found. Future research on this subject is recommended to clarify the exact relations between the concepts of emotion, acceptance and coping. Also, it's not clear how this differs from person to person. It could be researched how a certain coping style corresponds to the concept of OA acceptance.

Furthermore, Nikolaus et al. (2010) brought about the argument fatigue is linked to the amount of roles in woman and them reporting higher levels of fatigue and pain in RA patients. This relationship wasn't found clearly enough in this sample of OA patients. The sample of patients in this study comprises almost only women and so no reliable conclusion can be made regarding this proposition. Logically, it's also highly likely that this difference stems from the fact that this is another condition than RA. It is recommended for future research regarding this notion, that a more balanced sample gender is used and also a higher number of patients.

Additionally, some patients have noted feeling a bad understanding of their condition by their social environment, which clearly brings about a negative mood. It is possible, that the average social environment attributes the fatigue induced by OA is a mere symptom of natural aging. This is likely, since the average age of OA patients in this sample was 67 years. Kool (2011) states that, in social contract theory, reciprocal altruism assumes that the receiver of help is both willing and able to reciprocate support. In other words, helping the other back when he or she needs help too. It is important to note, that OA patients aren't always fully capable of helping others to the extent needed. This could be perceived as individuals who receive a benefit without paying a cost. Another possible explanation can be found in social support theory. According to this theory, social support promotes health and buffers the impact of external stressors on health (Kool, 2011). This implies that a lack of social support may be associated with worse health. Indeed, the relation between a lack of social support and worse health among patients with rheumatic diseases have been widely shown (Kool, 2011). This could explain the lack of social understanding in OA patients. This study points out it is indeed useful to pay attention to this concern. In terms of the professional environment, it could mean a higher effectiveness of interventions aimed at OA patients through, for example, better cooperation of patients. It is recommended for further research to adopt questions concerning the sense of being understood by the social environment, both professionally and in the form of close relatives.

In sum, this study points out that in OA the experience of fatigue and coping styles generally differ from one another, but proactive and anticipatory coping seems to be used by many patients. It's not yet clear what exact reasons could explain this. It could likely be that fatigue in OA is eventually unavoidable, so anticipatory coping (preparing oneself for a stressor that is yet to come) is rather logical. Not many other coping styles, logically reasoning, could be beneficial when the stressor can't be avoided. Furthermore, it could be likely that acceptance

influences OA as a whole in a psychological way (thus: fatigue experience, pain experience and emotions resulting from this). Patients have stated that acceptance 'makes dealing with OA in general just slightly easier' (see Acceptance in Results section). Thus, perhaps it is not so much the case of acceptance influencing one factor, which reduces fatigue indirectly via other factors, but a general positive influence on the patient's general well-being.

Limitations of this study are the asymmetrical gender in the sample (mostly women were used), because of which generalisation of the results is limited. Also, a mixed top-down and bottom-up scheme was used, which could include a pre-existing point of view in the coding process. Also, it is recommended to make use of a greater number of patients with less comorbidities. A positive aspect on the other hand is the view on possible positive sides of OA. Not much research has been done on the aspect of possibilities instead of limitations.

Further research regarding the subject is recommended to include the emphasis on possibilities of OA patients rather than the limitations. This study has shown that having a sense of being able to deal with OA via acceptance could play a positive role in dealing with the condition. Furthermore, the notions of social misunderstanding of OA patients points at e.g. adopting social communication courses in the education of professionals who deal with OA patients. A better sense of being understood could mean better cooperation of the patients in therapy for example. Also, it is recommended to take a more extensive look at the matter of why it is proactive coping that is so commonly used by OA patients.

REFERENCES

- Alswin, C., Levenson, M., Spiro, A. (1994). Vulnerability and resilience to combat exposure: can stress have lifelong effects?. *Psychology and Aging*, 9, 34 - 44
- Berg, A., Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133, 920 - 954
- Conaghan, P. (2008). Osteoarthritis – National clinical guideline for care and management in adults. Sudbury, Suffolk: The Lavenham Press Ltd.
- Fry, A.M., Martin, M. (1996). Fatigue in the chronic fatigue syndrome: a cognitive phenomenon? *Journal of Psychosomatic Research*, vol. 41, no. 5, 415 - 426
- Hewlett, S., Cockshott, Z., Byron, M., Kitchen, K., Tipler, S., Pope, D., Hehir, M. (2005). Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis Care & Research*, 53, 697 – 702
- Huyser, B.A., Parker, J.C., Thoreson, R., et al. (1998). Predictors of subjective fatigue among individuals with rheumatoid arthritis. *Arthritis Rheumatology*, 41, 2230 - 2237
- Kool, M.B. (2011). Understanding lack of understanding: Invalidation in rheumatic diseases. University of Utrecht, Utrecht.
- Lagace, C., Perruccio, A., DesMeules M., Badly E.M. (2003). The impact of arthritis on Canadians. *Arthritis in Canada: An Ongoing Challenge*, 7-31
- Lazarus, R.S., Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer.
- Nikolaus, S., Bode, C., Taal, E. (2010). New insights into the experience of fatigue among patients with rheumatoid arthritis: a qualitative study. *Annals of the Rheumatic Diseases*, 69, 895 – 897
- Ouwehand, C., Ridder, D.T.D. de, Bensing, J.M. (2007). A review of succesful aging models: proposing proactive coping as an important additional strategy. *Clinical Psychology Review*, 27, 873 - 884

Pollard, L.C., Choy, E.H., Gonzalez, J., et al. (2006). Fatigue in rheumatoid arthritis reflects pain, not disease activity. *Arthritis Rheum*, 45, 885 - 889

Power, D., Badley, E., French, M., Wall, A., Hawker, G. (2008). Fatigue in osteoarthritis: a qualitative study. *BMC Musculoskeletal Disorders*, 9, 63

Ridder, D.T.D. de., Schreurs, K.M.G. (1994). Coping en sociale steun van chronisch zieken. NCC-reeks Zorg, opvang en begeleiding van chronisch zieken. Zoetermeer: NCCZ

Schreurs, P.J.G., van de Willege, G., Brosschot, J.F., Tellegen, B., Graus, G.M.H. (1993). De Utrechtse Coping Lijst: Omgaan met problemen en gebeurtenissen. Lisse: Swets en Zeitlinger b.v.

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*, 10, 185 - 193

Wolfe, F. (1999). Determinants of WOMAC function, pain and stiffness, scores: evidence for the role of low back pain, symptom counts, fatigue and depression in osteoarthritis, rheumatoid arthritis and fibromyalgia. *Rheumatology (Oxford)*, 38, 355 - 361

Wolfe, F., Hawley, D.J., Wilson, K. (1996). The prevalence and meaning of fatigue in rheumatic disease. *Rheumatology*, 23, 1407 - 1417

Wolfe, F., Skevington, S.M. (2000). Measuring the epidemiology of distress: the rheumatology distress index. *J Rheumatology*, 27, 2000 - 2009

Zautra, A.J., Fasman, R., Parish, B.P., Davis, M.C. (2007). Daily fatigue in women with osteoarthritis, rheumatoid arthritis, and fibromyalgia. *Pain*, 128, 128 - 135

APPENDIX I

Interview introduction

Rémon Klein Woolthuis, 2012

Plaats, datum, handtekening

Interview ‘Vermoeidheidsbeleving bij artrose’**Introductie**

- Kort voorstellen (naam, studie)
- Doel onderzoek: ‘informatie verzamelen over de persoonlijke beleving van vermoeidheid bij mensen met artrose’
- Het gaat dus over wat voor impact vermoeidheid heeft en op welke manier het een rol speelt.
- Er zijn zeker geen goede of foute antwoorden; het gaat puur om uw beleving.
- Sommige vragen kunnen wat lastig zijn: het is geen probleem om verduidelijking te vragen en neem gerust de tijd om een antwoord te vinden.
- Verkregen informatie zal dus geheel anoniem verwerkt worden.
- Gemiddeld genomen zal het interview drie kwartier duren; dit kan wat langer of korter uitvallen, maar neemt u gerust alle tijd en voelt u zich aub niet gehaast.
- Er komen drie algemene delen aan bod: (1) Algemeen gedeelte, (2) ontwikkeling van diagnose en (3) uw omgang met vermoeidheid.
- Nogmaals: er is geen sprake van goede of foute antwoorden. Voelt u zich niet beoordeeld.

- Heeft u nog vragen?

Interview scheme

Onderzoeks vragen	Construct		Interviewvraag			Analyse
(Inleidend)	Inleidend/demografisch		Wat is uw leeftijd?			Tellen
	Inleidend rolanalyse		Wat is uw burgerlijke staat?			Citaat
	Inleidend rolanalyse		Heeft u kinderen?/ Hoeveel, hoe oud?/ Wonen zij nog thuis?			Tellen/Citaat
	Niet van toepassing	Gemiddeld meer dan 0 en minder dan 3 uur per week	Gemiddeld meer dan 3 en minder dan 10	Gemiddeld meer dan 10 en minder dan 20 uur per	Gemiddeld meer dan 20 en minder dan 30	Gemiddeld meer dan 30 uur per week

			uur per week	week	uur per week	
Werk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Studie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Huishouding (koken, boodschappen, was, schoonmaken)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Verzorging van mensen in eigen huishouding (bv. kinderen, zieke partner, ouder, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Verzorging van mensen buiten eigen huishouding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vrijwilligerswerk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tuinieren	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Huisdier/en	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Duur aandoening		Hoe lang heeft u artrose?		Notatie/citaat	
	Locatie aandoening		Zou u me kunnen vertellen op welke plek u artrose heeft?		Notatie/citaat	
	Klachtenbeschrijving		Wat voor klachten heeft u door uw artrose?		Tellen/citaat	
	Bijkomstig		Gebruikt u medicatie voor de artrose?		Tellen-citaat	
			<i>(Overgang: "Zou ik graag verder in diepte praten over hoe u uw vermoeidheid ervaart..")</i>			

Ervaring fatigue	Beschrijving	Heeft u last van vermoeidheid? Zo ja, zou u hiervan een beschrijving kunnen geven?	Tellen/citaat
	Ernst fatigue	Hoe hevig is uw gemiddelde vermoeidheid op een schaal van 1 tot 10 in de laatste 7 dagen (waarbij 1 = helemaal niet vermoeid en 10 = extreem vermoeid)	Tellen→ categorie/citaat
	Duur fatigue	Hoe lang houdt uw vermoeidheid gemiddeld aan?	Tellen→ categorie/citaat
	Frequentie fatigue	Hoe vaak komt deze vermoeidheid gemiddeld voor?	Tellen→ categorie/citaat
Coping	Inleidend	Zou u mij kunnen vertellen over hoe u met uw vermoeidheid omgaat over het algemeen? (indien variatie coping over tijd doorvragen)	Citaat
	(mogelijke) Variatie	Als u de ene keer op een concreet andere manier omgaat met uw vermoeidheid dan de andere keer, waaraan ligt dit volgens u?	Citaat
	OA in socialiteit	Wat voor een rol speelt artrose (en vermoeidheid) in uw relaties tot anderen?	Citaat
	Socialiteit	Zou u willen beschrijven wat voor een rol uw vriendenkring, kennissen en/of uw partner speelt bij uw omgang met vermoeidheid?	Citaat
	NA	Wat voor een rol speelt een negatief humeur bij uw omgang met vermoeidheid? Hoe komt dit precies volgens u?	Citaat

	PA	Wat voor een gevolg heeft een goed gemoed voor uw omgang met vermoeidheid?	Citaat
	Coping emoties	Wat zijn uw gevoelens over de artrose (en vermoeidheid)?	Citaat
	Coping emoties	Hoe gaat u over het algemeen met deze gevoelens om?	Citaat
	Coping emoties \leftrightarrow Fatigue	Staat de manier waarop u met uw gevoelens omgaat in verband met hoe vermoeid u zich voelt? Waarom, volgens u, is dit wel of niet zo?	Citaat
	Self-efficacy	Hoe ziet u zichzelf in hoe goed u met vermoeidheid om kunt gaan?	Citaat
	Gevolg Self-efficacy	Hoe staat in verband met hoe vermoeid u zich voelt?	Citaat
	Acceptatie	Kunt u mij vertellen over het accepteren van de artrose; hoe ziet u dit bij u zelf?	Citaat
	Gevolg Acceptatie	Heeft dit volgens u misschien ook invloed op hoe u met vermoeidheid omgaat?	Citaat
Afsluitend		<i>“Wilt u eventueel zelf nog iets toevoegen aan het gesprek? Zo nee, dan wil ik het gesprek graag bij deze afsluiten. Hoe hebt u het gesprek ervaren? Ik wil u bedanken voor dit gesprek.”</i>	

Appendix II

General taxonomy

Rémon Klein Woolthuis, 2012

1. General information (age, children, etc.)

Age
Number/age of children

2. Arthritis

Medication
Co-morbidity
Diagnosis
Level of fatigue in last 7 days
Pain

3. Experience of fatigue

Recovery
Cause
 -Weather
 -Mentally/physically
 -Pain
 -Miscellaneous
Duration
Severity
Frequency
Character
Development

4. Coping

Consistency
Emotion-focused
 -PA striving
 - Ignoring
 - Humor
 - Expressing
 - Relativating
Problem-focused
 - Activity
 - Resting
 - Temperature
 - Proactive coping
 - Physical
Self-efficacy
 -Self-confirmation
Miscellaneous

5. Sociality

Seeking help
Understanding

6. Emotion

Negative
Positive

7. Acceptance

No acceptance
Passive acceptance
Active acceptance
Dependent of (criteria)
Descriptive

Appendix III

Informed Consent (dutch)

Rémon Klein Woolthuis, 2012

Informed Consent**TOESTEMMINGSVERKLARING VOOR DEELNAME AAN HET
WETENSCHAPPELIJK ONDERZOEK: VERMOEIDHEID BIJ ARTROSE*****Waar gaat dit onderzoek over?***

Het doel van dit onderzoek is het verzamelen van informatie over de beleving van vermoeidheid bij de artrose. We zijn geïnteresseerd in (1) hoe de vermoeidheid bij artrose verandert vanaf het moment van diagnose tot aan het huidige moment en (2) hoe dit samenhangt met de manier waarop u ermee omgaat.

Binnen het kader van dit onderzoek zou ik graag een interview bij u af willen nemen. Het gaat bij dit interview om uw eigen beleving in verband met artrose en hoe dit een rol speelt en gespeeld heeft in uw leven. Daarom zal ik u straks een aantal vragen over verschillende aspecten stellen die gaan over uw artrose en de vermoeidheid die daarmee gepaard gaat. Eerst volgen enkele algemene vragen, hierna volgen vragen die met de ontwikkeling over tijd te maken hebben en tot slot hoe u ermee omgaat. Het is de bedoeling dat u vertelt over uw eigen mening, gevoelens en ervaringen met artrose. Er zijn geen goede of fouten antwoorden; het gaat echt om uw eigen ervaringen en meningen.

Wat betekent dit voor u?

Het interview zal ongeveer drie kwartier duren. Voor een latere analyse wordt dit interview opgenomen, maar uw gegevens blijven vertrouwelijk. In de verslaglegging is het mogelijk dat wij voorbeelden uit dit interview gaan gebruiken om bepaalde dingen uit te leggen of te verduidelijken, maar deze voorbeelden zullen dan *niet* aan uw gegevens gekoppeld worden. Alle informatie wordt dus anoniem verwerkt. Deelname aan dit onderzoek heeft geen consequentie voor eventuele behandeling op het ziekenhuis.

Geeft u toestemming?

Ik ben naar tevredenheid over het onderzoek geïnformeerd. Ik heb de schriftelijke informatie over het onderzoek goed gelezen. Ik ben daarbij in de gelegenheid gesteld om vragen over het onderzoek te stellen. Mijn vragen zijn naar tevredenheid beantwoord. Ik heb goed over deelname aan het onderzoek kunnen nadenken. Ik heb het recht mijn toestemming op ieder moment weer in te trekken zonder dat ik daarvoor een reden behoef op te geven. Ik heb het recht om altijd verdere vragen over het onderzoek of het interview te stellen. Ik stem ermee in dat het interview wordt opgenomen en dat geanonimiseerde voorbeelden uit het interview gebruikt worden in de verslaglegging.

Ik stem toe met deelname aan het onderzoek.

 Naam

24-10-11, Almelo