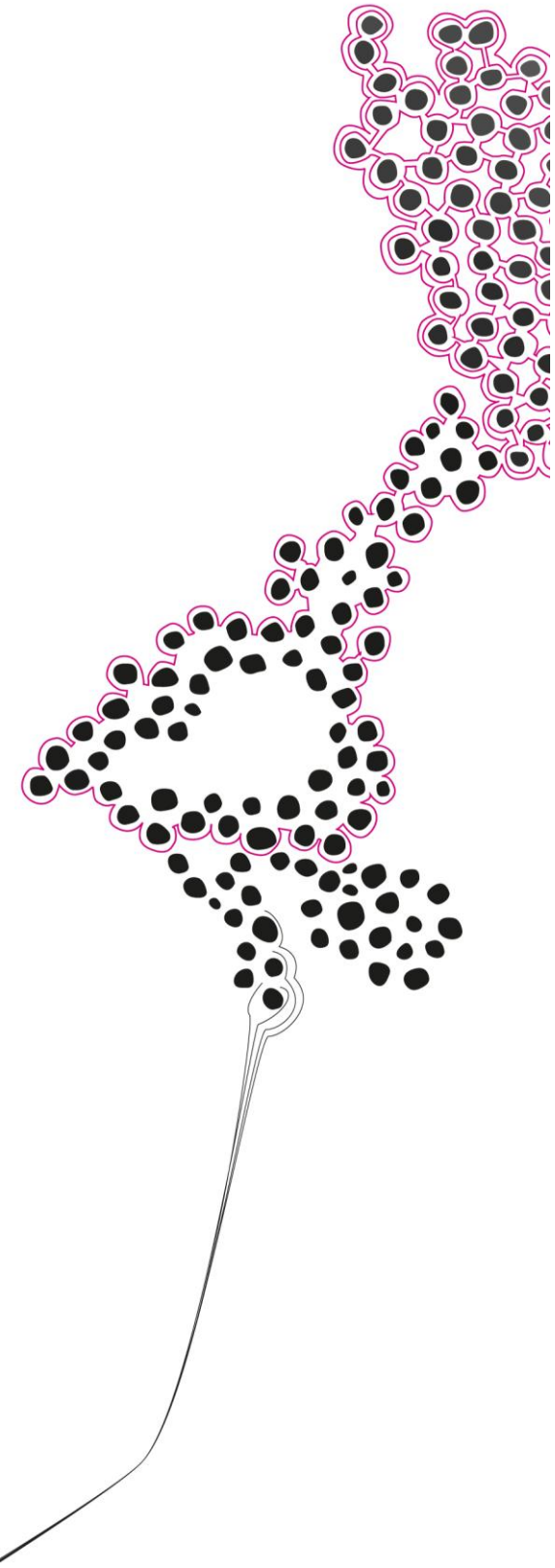
Bachelor Thesis



Unattainable goals of patients with rheumatoid arthritis: How goal disengagement and goal re-engagement can facilitate successful adaptation

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Abstract

Objectives - Rheumatoid arthritis patients are often faced with difficulties in accomplishing personal goals. This is due to characteristic disease symptoms such as pain, fatigue, stiffness, and the loss of function as well as the progressive course of disease. This longitudinal study examined the success of the goal management strategies goal disengagement and goal re-engagement in the change of indicators of adaptation to rheumatoid arthritis. These are depression, anxiety, purpose in life, positive affect, and satisfaction with participation and work participation. It was assumed that the goal management strategies remain stable over time. Furthermore it was expected that goal disengagement capacities lead to a positive change in depression and anxiety, while goal re-engagement capacities lead to a positive change in purpose in life, positive affect, and satisfaction with participation and work participation. Moreover it was supposed that a combination of both strategies leads to the most successful change in adaptation, because it approaches all factors of adaptation.

Methods – 181 patients suffering from rheumatoid arthritis participated in a questionnaire study. Two repeated measures analyses of variance were conducted to assess the stability of goal disengagement and goal re-engagement over the investigation period. Six hierarchical multiple-regression analyses were conducted to examine the relative importance of the goal management strategies for the change in adaptation, using two waves of data from a one year longitudinal study.

Results – Both goal management strategies remain stable over the investigation period. Goal disengagement capacities decreased the levels of depression over time. Beside of this no significant association was found between the goal management strategies and a change in adaptation. A combination of both strategies did not relate to a positive change in all adaptation factors, either.

Conclusion – The findings suggest no important role of goal adjustment capacities to the change in adaptation to rheumatoid arthritis, with the exception of goal disengagement concerning depression.

Samenvatting

Doelstelling – Patiënten met reumatoïde artritis ervaren vaak moeilijkheden in het bereiken van persoonlijke doelen. Verantwoordelijk daarvoor zijn symptomen zoals pijn, vermoeidheid, stijfheid en bewegingsbeperkingen. Deze longitudinale studie onderzocht het succes van de doel management strategieën, goal disengagement en goal re-engagement op de verandering in de factoren voor een aanpassing aan reumatoïde artritis. Deze factoren zijn depressie, angst, ervaring van een zinvol leven, positief affect, en tevredenheid met participatie en werk participatie. Het wordt verwacht dat de goal management strategieën over de tijd stabiel blijven. Bovendien wordt er vermoedt dat goal disengagement een positief effect heeft op de verandering in depressie en angst, terwijl goal re-engagement een positief effect heeft op de ervaring van een zinvol leven, positief affect en tevredenheid met participatie en werk participatie. Verder wordt verwacht dat een combinatie van beide strategieën het meest positieve effect op de verandering van de aanpassing heeft, omdat deze alle factoren van aanpassing inhoudt.

Methode – 181 patiënten met reumatoïde artritis participeerden in een vragenlijst studie. De stabiliteit van de twee doel management strategieën werd met hulp van een variantie analyse met herhaalde metingen gecontroleerd. Om het belang van de strategieën op de verandering van de aanpassing te onderzoeken zijn zes hiërarchische multiple regressie analysen uitgevoerd. Daarvoor worden gegevens van twee meetmomenten gebruikt, die in een longitudinaal studie van één jaar zijn verzameld.

Resultaten – Beide doel management strategieën bleven over de onderzoeksperiode stabiel. Goal disengagement had een positief effect op depressie en verlaagde het niveau ervan over de onderzoeksperiode. Behalve deze bevinding wordt geen significante associatie tussen de doel management strategieën en een verandering in adaptatie gevonden. Een combinatie van beide strategieën was niet aan een positieve verandering van alle factoren van aanpassing gerelateerd.

Conclusie – Deze bevindingen brengen geen belangrijke rol van doel management strategieën op de verandering van de aanpassing aan reumatoïde artritis naar voren. Een uitzondering is goal disengagement met betrekking tot depressie.

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Introduction

Chronic diseases are a widespread phenomenon. In the Netherlands one out of four people is affected by at least one chronic disease. This results into an amount of nearly 4.5 million chronic diseases (Nationaal Kompas Volksgezondheid, 2008). One type of disease which proceeds chronically is rheumatoid arthritis. This medical condition is the most common form of diseases falling under the generic term polyarthritis (Bijlsma & Voorn, 2000). All polyarthritic conditions have the inflammation of several joints, usually five or more, in the body in common (Arends, Bode, Taal, & Van de Laar, in press). The course of rheumatoid arthritis is mostly relapsing and differs from patient to patient (Reumafonds, n. d.; Bijlsma & Voorn, 2000). But yet inflammation is particularly to find in the tiny joints, namely in the hands and in the front of the feet, but can manifest itself in other, bigger joints as well (Nationaal Kompas Volksgezondheid, 2007). This is especially the case if radiological damage is found and if the course of the disease progresses. Beside radiological damage are pain, stiffness and the loss of function consequences of rheumatoid arthritis. Other symptoms patients often complain about are swellings of the affected joints, fatigue and loss of weight (Bijlsma & Voorn, 2000). The cause of rheumatoid arthritis is not yet clear, but it is assumed that it is multifactorial. A genetic vulnerability seems reasonable because rheumatoid arthritis is more often to be found in certain families and by twins of patients (Bijlsma & Voorn, 2000). This vulnerability implies a failure of regulatory mechanisms of the immune system, which usually suppresses an immunological reaction. If this system fails the defense cells will attack the own bodily tissue, leading to the chronic inflammation of the joints (Nationaal Kompas Volksgezondheid, 2007). Other possible causes include environmental and hormonal factors and smoking (Bijlsma & Voorn, 2000).

The progressive course of disease and the far reaching symptoms of rheumatoid arthritis have consequences for the daily life of these patients. They have to accept changes that can have negative effects on the quality of life and well-being (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). One important change due to a chronic disease is that patients find themselves in complete new situations. Their common coping styles are not proper anymore for a variety of these new situations (de Ridder et al., 2008). Coping styles are the general tendencies of people to react to events in a certain way (Morrison & Bennet, 2011). To adjust to their new situation, patients have to find new ways of coping. Adjustment means "… the healthy rebalancing by patients to their new circumstances" (de Ridder et al., 2011). These new circumstances are associated with the consequences of rheumatoid arthritis. One physical consequence is pain, a main symptom of the disease. To Scott, Smith, and Kingsley (2005) pain is a dominant concern of patients with rheumatoid arthritis and its persistence is a highly negative consequence of this disease. They also considered fatigue, another main symptom, as an important matter for the patients, too, because it is a prevailing factor in determining the quality of life and psychological aspects of daily functioning.

Rheumatoid arthritis has not just physical consequences for the affected people, but also psychological ones. Chronic illness often leads to negative emotions, amongst others depression and anxiety (de Ridder et al., 2008). Scott et al. (2005) point out that the pain of rheumatoid arthritis patients is closely associated with depression. Whereas other researchers found out that anxiety in rheumatoid arthritis patients is generally higher than in a comparable normative group, especially if the patients are depressed, too (Van Dyke et al., 2004.)

Besides physical and psychological consequences rheumatoid arthritis has functional consequences as well (Scott et al., 2005). The functional impairments worsen gradually as a pathway progressing in four steps. The first step is pathology which encompasses it in the broadest sense. Subsequently impairment reveals itself through dysfunctions which can already have an impact on functioning. Impairments are followed by functional limitations which mean a restriction in performing actions used in daily life and in many circumstances. The last step is disability, a difficulty in performing activities of daily life (Katz, Morris, & Yelin, 2006). This pathway progresses within only a few years (Scott et al., 2005). The fast progression and disability as the inevitable endpoint should illustrate how far reaching the functional consequences are. Katz et al. (2005) argue that the difficulty in performing activities of daily life encompasses several life domains. It has an impact on obligatory activities, which are required for survival of daily life and self sufficiency. These include daily living activities such as hygiene and using transportation or driving. Another domain touched by disability is the one of committed activities, which is associated with principle and productive roles. This domain encompasses child and family care, household responsibilities but also paid work. The last point, work disability, has been researched comprehensively by several researchers. De Croon and his colleagues (2004) considered among other aspects the economic side of work disability and argue that this common outcome of rheumatoid arthritis causes not only individual problems through loss of income and status, but also has societal consequences in terms of financial costs. Furthermore work disability has negative consequences besides economic ones for the affected individual. Patients with rheumatoid arthritis who are not able to work anymore report more pain and depression than those patients, who are able to continue paid work (Fifield, Reisine, & Grady, 1991). This negative affect seems to have an association with the fact, that “human beings are social animals by nature”. This wording stems from Reinhardt and Stucki (2007), who argue that this fact makes participation of central importance to individual quality of life and well-being. Participation enables the building and maintenance of resources such as social networks, social capital and support, self-esteem and self-efficacy, which are relevant to individual health. The last type of activities, which is accompanied by difficulties due to disability, are discretionary activities (Katz et al., 2006). This category encompasses activities such as socializing, exercise, engaging in leisure time activities and pastimes, participation in religious or spiritual activities, pursuing volunteer work or

hobbies, or other activities which relax people or bring them pleasure (Katz et al., 2005). The very nature of these activities makes a close link between discretionary activities and once again the concept of participation well evident.

The consequences of rheumatoid arthritis do not only involve the occurrence of new, negative consequences. Valued positive aspects of life can also decline. As already mentioned the loss of participation has negative impact on well-being and individual quality of life. Nevertheless it should also be mentioned that positive affect has positive influences on well-being, e. g. through lower levels of pain (Strand et al., 2007). Another important point is that rheumatoid arthritis patients have lower levels of purpose in life compared to healthy populations (Verduin et al., 2008). The concept of purpose in life describes a sense of directedness, a feeling that life has meaning. It outlines a clear comprehensibility of life's purpose. Furthermore it is the belief of having aims and objectives for living, whereby life goals play an important part (Ryff, 1989).

This overview of the consequences of rheumatoid arthritis shows that they are diverse and wide-ranging. Patients find themselves truly in new and unfamiliar circumstances, where adjustment is necessary. The adjustment model of de Ridder and her colleagues (2008) encompasses the majority of these consequences. They identify five key elements to effective adaptation: a) the performance of adaptive tasks, b) the absence of psychological disorders, c) the presence of low negative affect and high positive affect, d) adequate functional status, and e) the satisfaction and well-being in various life domains. Arends et al. (in press) modify the adequate functional status element slightly. They consider adequate functioning in several life domains and so they split functioning in participation in work life and in general participation. This distinction is in accordance with the different domains discussed with disability, namely committed and discretionary activities. The aim of the adjustment model is effective adaptation which ensures that the inevitable negative consequences of a disease do not gain the upper hand therefore the patient has the ability to deal successfully with the new situation and to live a full life. A full life involves dreams and goals, which one wants to realize. Certainly a chronic disease restricts people in their possibilities to achieve them. Nevertheless patients should not only be viewed in the light of the disease but also how their normal life proceeds. Due to the far reaching consequences of rheumatoid arthritis some of people's life goals must be abandoned. Research should also focus on how people adjust to those new circumstances.

One possibility to adjust to new circumstances are goal management strategies, which are supposed to reduce the discrepancies between the actual situation of the patient and his or her goals. These strategies are opportunities for action if certain difficulties appear while trying to reach a goal (Arends et al., in press). Wrosch, Scheier, Miller, Schulz, and Carver (2003b) studied the strategies of goal disengagement and goal re-engagement. They argue that these are important

factors when people face challenging circumstances which require adjustment of life goals. Goal disengagement, the giving up on goals, is especially important when people are confronted with goals that are not longer attainable (Wrosch et al., 2003b). Disengagement consists of two elements, the giving up of effort and the giving up of commitment. The reduction of efforts can be described as a lessening in energy directed toward goal attainment. The lessening can be partly, which means the person keeps trying but not as much as she used to, or complete, which means no energy is invested anymore to attain that goal (Wrosch, Scheier, Carver, & Schulz, 2003a). This facet of goal disengagement encompasses a more behavioral task for the person. One important advantage of giving up effort is that it frees personal resources, energy and time, on a long-term basis, that can be used for other areas of life (Wrosch et al., 2003b). For accomplishing the giving up of effort the second facet of goal disengagement, the giving up of commitment, is of importance. This is on the other hand a more emotional task. The person has to reduce the importance that is attached to the goal. In this way the goal is no longer seen as necessary for satisfaction in life (Wrosch et al., 2003a). This task involves a kind of emotional and mental acceptance that goals are not longer able to be reached. Furthermore this decommitment is likely to involve some reorganization of one's self-concept because it always comprises a change, more explicitly, a devaluation in at least one element of the self-concept (Wrosch et al., 2003a).

The content of the self-concept can not only be influenced by surrendering a goal. It can also be influenced by goal re-engagement (Wrosch et al., 2003a). This is the identification of other goals, the infusion of them with value, and the initiation of activities directed towards goal attainment. Engagement in new goals is important for the well-being of the patient, because it can minimize the distress that may arise from the desire to achieve the now unattainable goal. This is reached through a reduction of a person's failure-related thoughts and emotions. Furthermore new goals provide a sense of purpose in life because the patient finds other subjective meaningful activities that are important for the self. This sense of purpose in life can be expected to promote a person's long-term development. A great advantage of searching and pursuing new goals is that the person focuses on the positive issues of the new goal rather than on the prior failure (Wrosch et al., 2003b).

Furthermore goal management strategies have been studied in personality research and it emerged that they are relative stable differences in person's tendencies to cope with unattainable goals (Dunne, Wrosch, & Miller, 2011). Brandtstädter and Renner (1990) also examined the stability of goal management strategies. They researched two other goal management strategies, namely assimilation and accommodation. Assimilation encompasses intentional efforts to alter the actual situation in accordance to personal goals (Brandtstädter & Rothermund, 2002). This means that targeted objectives are maintained. Accommodation on the other hand involves an adjustment of goals. According to Brandtstädter and Rothermund (2002) this adjustment is due to constraints and

changes in the action resources. The two different models of goal management strategies seem to be partly complementary. Arends et al. (in press) hypothesized that goal disengagement is a facet of the broader strategy goal adjustment and found confirmation for this hypothesis. Due to this, findings concerning the stability of goal management strategies assimilation and accommodation seem to be applicable to goal disengagement and goal re-engagement. Brandtstädter and Renner (1990) and Brandtstädter and Rothermund (2002) studied accommodation and assimilation cross-sectionally resp. longitudinally. Both studies found that younger people are disposed to make use of assimilative strategies, while from their mid adulthood they make more use of accommodative strategies. These findings show that a change in goal management strategies is likely to occur during the lifespan. This encompasses several years. This study comprises a research duration of approximately one year. Because of this relative short duration it is assumed that the findings of Dunne et al. (2011) are more suitable for the present study. Therefore it is assumed that the strategies goal disengagement and goal re-engagement are relatively stable in the present research.

Although Brandtstädter and Rothermund (2002) studied assimilation and accommodation in a longitudinal research design, the goal management strategies goal disengagement and goal re-engagement were mainly studied cross-sectional. Furthermore most of the studies which aim to show the relationship between these goal management strategies and the consequences of a chronic disease are not based on the comprehensive adjustment model of de Ridder and her colleagues (2008); they mostly assessed just one of the five factors of successful adaptation. For example, Garnefski, Grol, Kraaij, and Hamming (2009) studied patients with Peripheral Arterial Disease and the influence of goal disengagement and goal re-engagement on their depressive symptoms. They found that goal re-engagement resulted in fewer depressive symptoms. Other researchers concentrated on the use of goal management strategies in conjunction with the well-being of women with rheumatoid arthritis (Plach, Heidrich, & Waite, 2003). Wrosch et al. (2003b) studied subjective well-being in different populations, namely undergraduates, young and older adults as well as parents of ill and healthy children. Neter and Miller (2009) combined aspects of distress and well-being in their study among multiple sclerosis patients which used goal disengagement and re-engagement, but studied only purpose in life as variable of well-being. These three studies showed positive associations between the use of goal management strategies and well-being. One study which used the model of de Ridder et al. (2008) in a slightly different version is those of Arends and her colleagues (in press). They assessed the use of goal management strategies in relation to the adaptation to polyarthritis in a cross-sectional study and found that the goal management strategies were important predictors of a successful adaptation.

However, longitudinal studies which assess the relationship between goal management strategies while combing several aspects of successful adaptation to chronic disease have yet to be

performed. This study examines the success of the goal management strategies goal disengagement and goal re-engagement for adjustment with several indicators of adaptation to rheumatoid arthritis in a longitudinal design. These are depression, anxiety, purpose in life, positive affect, and satisfaction with general as well as work participation. The present research is constrained to patients with rheumatoid arthritis because they form the greatest part of polyarthritis patients (Bijlsma & Voorn, 2000). Furthermore the goal management strategies goal disengagement and goal re-engagement were chosen because they were barely studied longitudinally; at least not in relation to rheumatoid arthritis. The present longitudinal research analyses three waves of data from a one year study of patients with rheumatoid arthritis.

Previous research has shown that goal disengagement strategies are especially useful to manage the negative consequences associated with the occurrence of unattainable goals. It can for example forecast less negative affect and fewer depressive symptoms (Wrosch et al., 2003b; Wrosch, Amir, & Miller, 2011). Dunne et al. (2011) consider these effects likely to occur because the strategy of goal disengagement can reduce negative mood by protecting persons from the experience of repeated failure. This is in line with the finding of Wrosch et al. (2003a) that a reduction of failure-related thoughts and emotions minimizes distress that arises from the desire to achieve the now unattainable goal. Goal re-engagement tendencies on the contrary are seldom directly related to negative mood states (O'Connor & Forgan, 2007; Wrosch et al., 2003b). Rather they contribute to the positive aspects of successful adaptation. Through providing new meaningful goals, goal re-engagement has been associated with purpose in life because patients find other personal meaningful activities (Dunne et al., 2011; Wrosch et al., 2003b). Dunne et al. (2011) describe also a relation between goal re-engagement and positive affect. This relation is likely to occur because the person's focus lies on the positive aspects of the new goal rather than on the prior failure (Wrosch et al., 2003b). This can lead to a more distinctive experience of positive feeling and emotion.

The present research takes up these findings but extends them, following the adjustment model of de Ridder et al. (2008), by more factors of successful adaptation, namely anxiety and participation. The main aim of this longitudinal study is to examine the success of the goal management strategies goal disengagement and goal re-engagement for a change in adjustment with indicators of adaptation to rheumatoid arthritis. Regarding the relatively short investigation period of one year the following hypotheses (except hypothesis 1) bear upon changes between measurement 1 and measurement 3. It is assumed that differences in this period of time are more pronounced than between measurements 1 and 2 and measurements 2 and 3.

1. The first hypothesis of the present research states that the goal management strategies goal disengagement and goal re-engagement are stable over the three measurements.

2. The second hypothesis states that higher levels of goal disengagement relate solely to distress of managing an unattainable goal. It is expected that abandoning of an unattainable goal leads to a positive change in the adaptation to rheumatoid arthritis concerning depression and anxiety. Therefore lower levels of depression and anxiety are supposed at the last measurement.
3. Further it is hypothesized that higher levels of goal re-engagement relate solely to facets of well-being. Therefore re-engagement leads to positive change in the adaptation to rheumatoid arthritis concerning purpose in life, positive affect and participation. Higher levels of purpose in life, positive affect and participation are expected at the last measurement.
4. Because successful adaptation is, as mentioned earlier, a combination of positive consequences and the absence of negative consequences, the combination of goal disengagement and goal re-engagement as an interaction effect should lead to the most positive change in successful adaptation. It is expected that this leads to lower levels in depression and anxiety, as well as higher levels of purpose in life, positive affect and participation at measurement three.

Method

Sample and Procedure

The data for this questionnaire study were obtained from a study with several forms of polyarthritis. The participants were selected from an outpatient clinic for rheumatology. This clinic maintains an electronic diagnosis registration system from which 803 patients were selected at random. Patients could only be included in the sample if they fulfill the following inclusion criteria: 1. The patient is diagnosed with polyarthritis, 2. The patient is 18 years or older, 3. The patient is able to fill in the questionnaire in Dutch (either on her/his own or with help) and 4. The patient is receiving treatment for polyarthritis. If all of the 803 selected patients match the four inclusion criteria they were allowed to participate in the program, which was checked by the rheumatologists. 164 patients were not approached in this study because they did not fulfill these criteria, thus 639 were patients included in the study. The included patients received an invitation letter, an informed consent form and the questionnaire. 305 informed consent forms and questionnaires were received in time. This is a response rate of 48 %.

This study made use of the data from this study but included only patients with a diagnosis with either rheumatoid arthritis alone or rheumatoid arthritis among other forms of polyarthritis. A comprehensive overview of the other forms of polyarthritis and other forms of comorbidity of which the participants suffer can be found in Table 2. Out of the 305 patients, 181 were patients with the diagnosis rheumatoid arthritis. The demographic characteristics of the participants at measurement 1 are shown in Table 1.

Table 1.

Demographical Characteristics of the Participants with Rheumatoid Arthritis at Measurement 1 (n=181)

Sex, *n* (%)	
Male	63 (34.8)
Female	118 (65.2)
Age (years) mean (SD), range	60 (12.23), 24 – 85
Marital status, *n* (%)	
Unmarried / not cohabitating	12 (6.6)
Unmarried/ cohabitating	10 (5.5)
Married	120 (66.3)
Widow/ widower	21 (11.6)
Divorced	14 (7.7)
Missing	4 (2.2)
Educational level, *n* (%)[a]	
No / lower	69 (38.1)
Secondary	75 (41.4)
Higher	33 (18.3)
Missing	4 (2,2)
Work status, *n* (%)	
Fulltime work	26 (14.4)
Part time work	30 (16.6)
Keeping the house	27 (14.9)
Unemployed	9 (5.0)
Unfit for work	26 (14.4)
Retired	60 (33.1)
Missing	3 (1.7)

[a] Low: No education, primary school or lower vocational education; Middle: high school and middle vocational education; High: high vocational education and university

Table 2.

Clinical Characteristics of the Participants at Measurement 1 (n=181)

Duration of Disease (years) mean (SD), range	13.85 (11.89), 1 - 70
Other forms of polyarthritis *n* (%)[a]	
Arthrothis	18 (9.9)
SLE	3 (1.7)
Fibromyalgia	6 (3.3)
Arthropathic psoriasis	6 (3.3)
Gout	4 (2.2)
Chronic back pain	12 (6.6)
Osteoporosis	8 (4.4)
Bekhterev's disease	2 (1.1)
Other	2 (1.1)
Other forms of comorbidity, *n* (%)[a]	
Infectious disorder	3 (1.7)
Malicious disease or cancer	9 (5.0)
Blood disease or disease immune system	5 (2.5)
Metabolic disorder	18 (10.1)
Psychological disorder	8 (4.5)
Disorder of the nervous system	3 (1.7)
Sensory disorder	31 (17.3)
Disorder of the cardiac or circulatory system	29 (16.2)
Disorder of the respiratory tract	17 (9.5)
Disorder of the digestive system	20 (11.2)
Disorder of the skin	23 (12.8)
Disorder of urinary or genital	18 (10.1)
Allergy	10 (5.6)
Injury / intoxication / results of an accident	4 (2.2)
Other	39 (21.8)

[a] Multiple responses allowed

Measures

The questionnaire assessed demographical and clinical variables, including sex, age, marital status, education, employment, comorbidity, and duration of disease. Aside from that it consisted of several (parts of) questionnaires, measuring different constructs. The recent study did not make use of all questionnaires of the original version but included only the questionnaires which measure the relevant variables. These are goal disengagement and goal re-engagement capacities and the

adaptation indicators anxiety, depression, purpose in life, positive affect, participation and work participation.

Goal disengagement and goal re-engagement. These goal management strategies were measured across the three waves with the 10-item Goal Adjustment Scale (GAS) (Wrosch et. al, 2003b). Participants were asked to indicate how they usually react when they have to stop pursuing an important goal in their life. The questionnaire consists of two subscales, measuring the two strategies. Four items assess the strategy goal disengagement (1, 3 reversed, 6 reversed, 8). An example for an item of this scale is 'It's easy for me to stop thinking about the goal and let it go'. Goal re-engagement is measured with 6 items (2, 4, 5, 7, 9, 10), e. g. 'I start working on other new goals to pursue'. Participants were asked to report their answers on 5-point Likert-type scales, ranging from 'strongly disagree' (1) to 'strongly agree' (5). Two sum scores need to be calculated for each subscale apart. The sum score for the goal disengagement scale is calculated by adding up the values of its four items considering the two items which need to be reverse coded. The same is done for the six items of the goal re-engagement scale. A higher value on these scales indicates higher levels of those strategies. Cronbach's alpha was calculated for the two subscales apart and for the three measurements apart as well. For the goal disengagement subscale Cronbach's alpha ranged from .52 to .65. The goal re-engagement subscale resulted in better values, with Cronbach's alpha ranging from .89 to .90 (see table 3).

Depression and anxiety. The levels of depression and anxiety of the rheumatoid arthritis patients were at all three measurements assessed with the 14-item Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). This questionnaire is suitable for general medical populations and can be completed by patients of 16 years or older. Participants were asked to report how they have felt during the last week on 4-point Likert-type scales with different answering categories which fit the different types of statements. They ranged e. g. from 'mostly' (0) to 'not at all' (3) or from 'often' (0) to 'very seldom' (3). The HADS consists of two subscales, one measuring depression (2, 4, 6 reversed, 8 reversed, 10 reversed, 12, 14), the other measuring anxiety (1 reversed, 3 reversed, 5 reversed, 7, 9, 11 reversed, 13 reversed). Sample items included for the depression subscale are e.g. 'I feel as I if I am slowed down' and for the anxiety subscale 'I feel restless and have to be on the move'. This study included a fifteenth item about the use of antidepressants as well. Rheumatoid arthritis patients should indicate if they made use of this sort of medicine, prescribed by a doctor. They could answer this question with yes or no. Sum scores need to be calculated for the anxiety and depression subscale apart by adding up the values of their items, considering the reversed coded ones. Each subscale can have a sum score between 0 and 21, whereby higher values indicate higher

levels of anxiety resp. depression. The additional fifteenth item is not integrated in the calculation of the sum scores and can be considered as being unrelated to the HADS. For the two subscales as well Cronbach's alpha was calculated separately for the three waves. The values for the anxiety subscale ranged from .79 to .83. The depression subscale has Cronbach's alphas ranging from .64 to .82 (see table 3).

Purpose in life. Purpose in life was also assessed across the three waves. The measuring instrument used was the Purpose in Life Questionnaire (PIL), consisting of 6 items (2 and 3 reversed), e. g. 'Some people wander aimlessly through life, but I am not one of them' (Ryff, 1989a; Ryff & Keyes, 1995). Participants were asked to report how they experience their life as a whole on 5-point Likert-type scales, ranging from 'strongly disagree' (1) to 'strongly agree' (5). The sum sore is calculated by adding up all item scores, considering the revered ones. A higher value indicates higher values of pupose in life. The Cronbach's alpha for purpose in life ranged from .76 at the last measurement to .81 at the first (see table 3).

Positive affect. Positive affect was measured with one subscale of the Positive and Negative Affect Schedule (PANAS) on the three waves (Watson, Clark & Tellegen, 1988). This study made only use of the ten items which measure positive affect. The ten items consist of just one word, describing a feeling or emotion; examples are 'active' and 'proud'. The patients should indicate how they have felt during the last week Answers were reported on a 5-point Likert-type scale, ranging from 'very slightly or not at all' (1) to 'very much' (5), whereby a higher value indicated higher commitment to the emotion or feeling. The sum score of the PANAS is calculated by adding up the item scores to one total score. The higher this score, the more positive affect is experienced. Cronbach's alpha was calculated for the positive affect scale as well. It recorded the quite high value of .93 at all three measurements (see table 3).

Participation. The Questionnaire Impact on Participation and Autonomy (IPA) was used to assess the levels of participation of the patients and was administered at the three waves as well. This questionnaire asks the participants to what extent they are satisfied with their own participation and autonomy. Therefore it is aimed to assess the subjective point of view of the patients and not to give an objective appraisal. This questionnaire can be completed by persons 18 years or older and is validated for persons with different chronic disorders. This study made use of a shortened version of the original questionnaire. It included four different domains, namely family role, social life and relationships, work and education as well as autonomy outdoors. It consisted of 25 items which were rated on 5-point Likert-type scales, ranging from 'very good'(0) to 'very poor' (4). Examples of items

are ‘My chances of getting around in my house *when* I want to are:’ and ‘The respect I receive from people who are close to me is:’. Sum scores need to be calculated for every subscale apart. To calculate the role score the values of each subscale are added up and divided through the number of items answered by the participant. This procerdure requires an answering rate of 75 % at the minimum. A score of ‘0’ indicates no limitation in autonomy, a score of ‘4’ indicates very poor autonomy. This study follows the model of Arends et al. (in press) and adds together the subscales family role, social life and relationships and autonomy outdoors to form one variable, namely (general) participation. Therefore this study uses two variables for the IPA questionnaire, participation and work participation. Eventually the values of Cronbach’s alpha were calculated apart for the three different measurements and the two variables. Participation ranged from .93 to .94. and work participation had Cronbach’s alphas between .80 and .90 (see table 3).

Internal Consistencies of the Used Scales

The number of participants, means, standard deviations and the Cronbach’s alphas of the different scales at the three measurements can be found in Table 3.

Table 3.

Number of Participants and Cronbach’s Alphas for all Three Measurements

Scale	Measurement 1 *n*, *α* mean (SD)	Measurement 2 *n*, *α* mean (SD)	Measurement 3 *n*, *α* mean (SD)
Goal disengagement (GAS)	176, .52	156, .65	146, .64
	11.72 (2.24)	11.66 (2.41)	11.85 (2.48)
Goal re-engagement (GAS)	175, .89	155, .90	147, .89
	21.42 (3.69)	21.85 (3.52)	21.81 (3.52)
Anxiety (HADS)	179, .83	157, .79	143, .83
	5.20 (3.58)	4.97 (3.49)	4.96 (3.49)
Depression (HADS)	178, .80	158, .64	145, .82
	4.48 (3.50)	4.30 (3.57)	4.34 (3.58)
Purpose in Life (PIL)	178, .81	157, .80	146, .76
	22.05 (3.66)	22.19 (3.66)	22.01 (3.39)
Positive affect (PANAS)	178, .93	152, .93	145, .93
	34.63 (7.34)	35.23 (6.87)	35.16 (6.98)
Participation (IPA)	171, .94	151, .94	145, .93
	1.31 (0.63)	1.31 (0.63)	1.30 (0.63)
Participation work (IPA)	28, .90	31, .83	32, .80
	1.40 (0.85)	1.47 (0.83)	1.46 (0.70)

Analyses

For the statistical analyses version 21 of the Statistical Package for Social Sciences (SPSS) was used. To examine if the two goal management strategies change over the three measurements two separate repeated measures analyses of variance were conducted. These analyses incorporated the within-subject factor *Time* and the scores of the goal management strategies goal disengagement and goal re-engagement across the three waves as dependent variable respectively.

To test the other research questions regarding the relation of goal disengagement and goal re-engagement with adaptation, separate hierarchical regression analyses were conducted, for each of the six adaptation factors respectively. Beforehand a Pearson Correlation Table was created for the control variables (baseline level of the adaptation factor, sex, age, disease duration, and comorbidity) as well as for the goal management strategies (goal disengagement and goal re-engagement) at measurement 1 and the factors of adaptation (anxiety, depression, purpose in life, positive affect, participation and work participation) at measurement 3. This can be viewed as preparatory work for the regression analysis to make correlations and their level of significance visible. The control variable comorbidity was created through adding up the other forms of polyarthritis and other forms of comorbidity for each person. The presence of each form of comorbidity was scored with 1, the non presence with 0. Because multiple responses were possible the value of this variable indicates the number of comorbidities a patient has.

Moreover collinearity diagnostics were analyzed to confirm that there are no serious problems with multicollinearity. The used measure was the variance inflation factor (VIF) that rates how much the variance of an estimated regression coefficient increases if correlations between predictors are present. VIF values of 1 denote that no factors are correlated. Most VIFs were about 1.1 to 1.9, the highest value was 2.9. These values indicated some correlation, but none to be concerned about. For conducting the regression analyses, the scores of the six adaptation factors of measurement three were used as dependent variables. The first step of the hierarchical regression analyses controlled for the baseline levels of the six adaptation factors, thus using the scores of measurement one. In the second step of the analyses the main effects of participants' baseline levels of the goal management strategies goal disengagement and goal re-engagement were included. In the final step of the hierarchical regression analyses the interactions between goal disengagement and goal re-engagement at the baseline level were tested for significance. The interaction variable was created as follows: At first mean scores for the sum scores of goal disengagement and goal re-engagement at the baseline level were calculated. Thereafter centered variables for goal disengagement and goal re-engagement were created through subtracting the respective mean score from the baseline level sum score. Lastly the both centered variables of goal disengagement and goal re-engagement were multiplied to form the interaction term. The results of the hierarchical

regression analyses were controlled for participant's sex, age, duration of disease and comorbidity. To ensure that a regression analysis may be conducted the normal distribution of the respective scale scores was checked in advance and this requirement was met.

Results

The results are described in four sections. The first section shows the number of participants and Cronbach's alphas at the three measurements. The second section reports whether goal disengagement and goal-re-engagement change over time. The third section indicates Pearson Correlations between the two strategies and the factors of adaptation. And the last section examines the control variables and the main and interaction effects of the two strategies in predicting changes in the five adaptation factors over time.

Stability of Goal Management Strategies over One Year

To examine possible changes in the goal management strategies goal disengagement and goal re-engagement two separate repeated measures analyses of variance were conducted. The analysis for goal disengagement demonstrated no significant linear difference of the within-subject factor time, F (2, 244) = .80, p > .05. Neither did the repeated measures analysis of variance for the strategy goal re-engagement, F (2, 266) = .35, p > .05. These results indicate that the two goal management strategies did not change over time and hence are relatively stable. This finding is also supported by the relatively stable means of both strategies, which can be found in Table 3.

Pearson Correlation between Control Variables, Goal Management Strategies, and Adaptation Factors

Control variables. The control variable age showed a significant but weak relation with the adaptation factor depression (all correlations can be found in Table 4.). This finding denotes that an increase in age is associated with an increase in depression. Moreover significant but weak negative correlations were found between age and purpose in life and positive affect. This means that lower levels of purpose in life and positive affect are associated with an older age. The control variable disease duration showed a significant positive but weak relation with depression. This finding indicates that longer disease duration is associated with higher levels of depression. Comorbidity showed a significant positive but weak correlation with depression, too. This means that more comorbidity is associated with higher levels of depression. Furthermore comorbidity showed moderate significant relations with participation and work participation. These findings denote that

more comorbidity is associated with higher levels of satisfaction with participation and work participation.

Goal disengagement. Goal disengagement showed significant but weak negative relations with anxiety, depression, and participation. This indicates that higher levels of this goal management strategy are associated with lower levels of anxiety, depression and satisfaction of participation.

Goal re-engagement. This goal management strategy showed significant but weak negative correlations with anxiety and participation. Furthermore goal re-engagement showed significant moderate negative relations with depression and work participation. These findings indicate that higher levels of goal re-engagement are associated with lower levels of anxiety, depression, and satisfaction with participation and work participation. In addition to that this goal management strategy showed weak to moderate positive correlations with purpose in life and positive affect. These findings denote that higher levels of goal re-engagement are associated with higher levels of purpose in life resp. positive affect.

Table 4.

Pearson Correlation between Control Variables, Goal Management Strategies, and Adaptation Factors

Variable / measurement	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
Control variables / measurement 1												
1. Sex	-											
2. Age	-.14	-										
3. Diseae Duration	.10	.23**	-									
4. Comorbidity	.10	.12	.06	-								
Goal management strategies / measurement 1												
5. Goal disengagement	-.01	.25**	.03	-.11	-							
6. Goal re-engagement	.09	-.10	.02	.01	.33**	-						
Adaptation factors / measurement 3												
7. Anxiety	-.07	.11	.14	.16	-.21*	-.26**	-					
8. Depression	-.10	.20*	.17*	.22**	-.20*	-.31**	.65**	-				
9. Purpose in Life	.09	-.19*	.03	-.12	.07	.34**	-.43**	-.61**	-			
10. Positive affect	-.02	-.22**	-.00	-.14	-.01	.25**	-.48**	-.61**	.69**	-		
11. Participation	.08	.14	-.01	.41**	-.17*	-.27**	.47**	.68**	-.59**	-.64**	-	
12. Participation work	-.00	.16	-.10	.47**	-.05	-.33**	.56**	.62**	-.58**	-.59**	.73**	-

* Correlation is significant at the .05 level (2-tailed). ** Correlation is significant at the .01 level (2-tailed)

Multivariate Relationships between Goal Management Strategies and Adaptation Factors

To examine the relationship between goal disengagement and goal re-engagement and the five indicators of adaptation over time, six separate hierarchical regression analyses were conducted. In each case the predictive value of control variables was investigated in the first model. In the second model the two goal management strategies were added and in the last block the interaction effect of the two strategies was integrated. Tables 5 – 10 give comprehensive overviews of the individual hierarchical regression analyses. A short description including the most important findings can be found under each table.

Table 5.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Anxiety

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.65	.42		18.64**	
Baseline Anxiety	.66**	.63**	.64**					
Demographical								
Sex	.01	.01	.00					
Age	.10	.11	.12					
Disease related								
Disease duration	.19**	.18**	.18**					
Comorbidity	-.09	-.10	-.09					
Goal management strategies				.65	.42	.01	13.40**	.55
Goal disengagement		-.07	-.07					
Goal re-engagement		-.03	-.01					
Interaction of strategies			.04	.65	.43	.00	11.71**	.55

*p ≤ 0.05, **p ≤ 0.01

Anxiety. The baseline level of anxiety (model 1) had significant predictive value of anxiety at the last measurement and was the greatest predictor of all control variables. Disease duration as one of the disease related variables had significant predictive value, too. Demographical variables showed no significant contribution to anxiety. Together the control variables explained 42 % of the variance in anxiety (model 1). None of the two goal management strategies showed a significant contribution to anxiety (model 2). Together they explained 1 % of the variance in anxiety. The third model of this regression analysis showed that the interaction of goal disengagement and goal disengagement added no significant contribution to the prediction of anxiety (model 3).

Table 6.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Depression

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.71	.50		26.84**	
Baseline Depression	.68**	.68**	.68**					
Demographical								
Sex	-.06	-.07	-.07					
Age	.09	.13	.13					
Disease related								
Disease duration	.12*	.11	.11					
Comorbidity	-.03	-.05	-.05					
Goal management strategies				.72	.52	.02	20.40**	.07
Goal disengagement		-.16*	-.16*					
Goal re-engagement		.04	.04					
Interaction of strategies			.00	.72	.52	.00	.17.72**	.96

*p ≤ 0.05, **p ≤ 0.01

Depression. Of the control variables only the baseline level of depression had significant predictive value of measurement 3 levels of depression (model 1) The control variables explained 50 % of the variance in depression.. Goal disengagement showed a significant contribution to depression (model 2) and this contribution persists when the interaction effect of both strategies was entered with in model 3. Goal disengagement and goal re-engagement together added 2 % to the explanation of depression. The interaction effect of these both strategies added no significant contribution to the prediction of depression (model 3).

Table 7.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Pupose in Life

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.61	.37		15.16**	
Baseline Purpose	.59**	.56**	.58**					
Demographical								
Sex	.05	.04	.05					
Age	-.15*	-.16*	-.17*					
Disease related								
Disease duration	.01	.02	.02					
Comorbidity	.05	.06	.06					
Goal management strategies				.61	.38	.01	11.12**	.36
Goal disengagement		.06	.07					
Goal re-engagement		.07	.04					
Interaction of strategies			-.05	.62	.38	.00	9.75**	.51

*p ≤ 0.05, **p ≤ 0.01

Purpose in Life. Two of the control variables had a significant predictive value of purpose in life at measurement 3. The baseline level of purpose in life showed the greatest predictive value and the demographical variable age had predictive value, too. Together the control variables together explained 37 % of the variance in depression (model 1). Neither goal disengagement nor goal re-engagement showed a significant contribution to purpose in life (model 2). They added 1 % to the explanation of depression. The interaction effect of both strategies added no significant contribution to the prediction of depression. The Δ $R^2$of the interaction effect was .00. (model 3).

Table 8.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Positive Affect

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.67	.45		21.46**	
Baseline Pos. Affect	.63**	.61**	.63**					
Demographical								
Sex	.02	.00	.02					
Age	-20**	-.19**	-.20**					
Disease related								
Disease duration	.00	.00	-.01					
Comorbidity	-.03	-.03	-.03					
Goal management strategies				.67	.45	.00	15.29**	.69
Goal disengagement		.00	.02					
Goal re-engagement		.06	.03					
Interaction of strategies			-.09	.68	.46	.01	13.60**	.24

*p ≤ 0.05, **p ≤ 0.01

Positive affect. The control variables together explained 45 % of the variance in positive affect and the baseline level of positive affect showed the greatest predictive value. Age also had significant predictive value (model 1). None of the goal management strategies showed a significant contribution to positive affect. They added 0 % to the explanation of variance (model 2). The interaction of goal disengagement and goal re-engagement added 1 % to the explanation of variance but had no significant predictive value (model 3).

Table 9.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Participation

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.78	.61		42.60**	
Baseline Part.	.74**	.74**	.75**					
Demographical								
Sex	.07	.07	.07					
Age	.07	.07	.08					
Disease related								
Disease duration	-.03	-.03	-.03					
Comorbidity	.06	.06	.06					
Goal management strategies				.78	.61	.00	29.98**	1.00
Goal disengagement		.01	-.00					
Goal re-engagement		-.00	.02					
Interaction of strategies			.05	.78	.61	.00	26.24**	.44

*p ≤ 0.05, **p ≤ 0.01

Participation. The baseline level of participation (model 1) had significant predictive value of participation at measurement 3 and was the only significant predictor of all control variables. R^2 of the first model was .61. Neither the goal management strategies (model 2) nor their interaction effect (model 3) showed significant predictive value. The Δ R^2 of both models was .00.

Table 10.

Results of the Hierarchical Regression Analysis for the Adaptation Factor Work Participation (n=28)

Predictor	Model 1 (β)	Model 2 (β)	Model 3 (β)	R	R^2	ΔR^2	F	ΔF
Variables of Control				.75	.56		10.84**	
Baseline Work P.	.59**	.62**	.59**					
Demographical								
Sex	.07	.05	.07					
Age	-.04	-.13	-.14					
Disease related								
Disease duration	-.10	-.09	-.08					
Comorbidity	.22	.20	.20					
Goal management strategies				.78	.61	.06	9.34**	.06
Goal disengagement		.28*	.55**					
Goal re-engagement		-.13	-.16					
Interaction of strategies			-.34*	.82	.66	.05	9.88**	.02

*p ≤ 0.05, **p ≤ 0.01

Work participation. The regression analysis of the adaptation factor work participation was conducted with fewer cases than the other regression analyses, namely with 28 cases. The control variables together explained 56 % of the variance in work participation. The only control variable with significant predictive value was the baseline level of work participation (model 1). When the goal management strategies were added to the control variables the explained variance increased with 5 %. Goal disengagement was a significant predictor (model 2) and the predictive value remains significant when the interaction of both strategies was added (model 3). The interaction effect of both variables showed also a significant contribution to work participation (model 3). R^2 of the final model was .66 and Δ R^2 .05.

Discussion

The present longitudinal study examined the contribution of the goal management strategies goal disengagement and goal re-engagement to a change in adjustment with indicators of adaptation to rheumatoid arthritis. These were anxiety, depression, purpose in life, positive affect and general as well as work participation. Generally speaking the goal management strategies did not contribute to a change in successful adaptation in this study.

The first hypothesis stated that the two goal management strategies are stable over the three measurements. The reported results support this hypothesis; both goal management strategies

showed no significant change during the investigation period of one year. This finding corresponds to the results of Dunne et al. (2011) that goal disengagement and goal re-engagement are relative stable differences in person's tendencies to cope with unattainable goals.

The second hypothesis aimed at the influence of goal disengagement on a positive change in successful adaptation. It was assumed that this strategy is especially useful to manage the negative consequences associated with the occurrence of unattainable goals. Higher levels of goal disengagement were supposed to lead to lower levels of anxiety and depression one year later. This hypothesis was partly supported by the results of this study. Participants who showed higher levels of the tendency to abandon goals had lower levels of depression at the last measurement and thus showed a weak positive change in their adaptation concerning depression. For anxiety this hypothesis was not confirmed. Although there was an association between goal disengagement and anxiety, the goal management strategy was not linked to a change in anxiety afterwards; goal disengagement did not seem to have influence on the change of levels of anxiety. This may be due to the fact that anxiety has influence on disengagement and not vice versa. This means that the association between anxiety and goal disengagement came about because the levels of anxiety had influence on the levels of goal disengagement. It may be possible that people with higher levels of anxiety are less prone to abandon goals. It can be the case that anxious people have the tendency to be afraid of changes in their lives, too and thus stick to their goals. Furthermore a third variable problem cannot be ruled out, either. This implies that another, unmeasured variable may better explain the relation between both variables, even if goal disengagement does not influence the levels of anxiety and vice versa. A third variable can be related to one or both variables, but it can also cause changes in both of the other variables. Possible third variables in the association between anxiety and the giving up on goals can be pain or fatigue, which are predominant symptoms of rheumatoid arthritis. It can be the case that, e. g. fatigue leads people to disengage less often from goals and to experience higher levels of anxiety. The fatigue of rheumatoid arthritis patients may be associated with a feeling of powerlessness which causes restrictions in the routine activities of patients. People can feel more anxiety because they do not know if these restrictions remain or even get worse. Additionally the fatigue and the accompanying powerlessness can cause people to surrender goals less often. Goal disengagement is likely to involve a reorganization of the self-concept, which may be too demanding for people with higher levels of fatigue. The emotional and mental acceptance that goals are no longer attainable may consume energy that is not available to the patient. Further research can investigate this relation more pronounced.

The results of this study are in accordance with findings of studies that examined the relationship between goal management strategies and successful adaptation, not the change in adaptation. The results of Dunne et al. (2011) and Wrosch et al. (2011) show, that goal

disengagement can lessen the experience of depression among individuals who encounter unattainable goals. Therefore it can be assumed, that the ability to withdraw effort and commitment from unattainable goals can help to protect rheumatoid arthritis patients from experiencing depressed mood states. This relation seems plausible, due to the fact that goal disengagement protects patients from the experience of failure (Dunne et al., 2011). Additionally this study showed that goal disengagement does not only lessen the experience of depression but that this lessening remains constant. People who tend to abandon unattainable goals improve over time concerning their depressed mood states.

The study of Arends et al. (in press) found relations between goal disengagement and lower levels of anxiety. But Arends and her colleagues studied the relationship between goal management strategies and successful adaptation cross-sectionally. This means they examined the success of the goal management strategies on adaptation at a single point of time. Their findings demonstrate that goal disengagement is related to lower levels of anxiety; people who have higher levels of the tendency to abandon unattainable goals show lower levels of anxiety. However, the present study made use of a longitudinal design and assessed the change in adaptation over time. It was found that higher but unchanging levels of goal disengagement do not contribute to a positive change in adaptation concerning anxiety. Therefore it can be the case, that abandoning unattainable goals can lessen the feelings of anxiety; but that further improvement does not take place. This may be due to the fact that people's tendency to separate from unattainable goals remains constant (see hypothesis 1) and this constant level is not able to reduce feelings of anxiety further, at least not significantly.

The third hypothesis concentrated on the influence of goal re-engagement on a change in adaptation. It was assumed that goal re-engagement tendencies relate to facets of well-being. Therefore higher levels of goal re-engagement were supposed to lead to higher levels of purpose in life, positive affect and satisfaction with general and work participation one year later. The reported results did not support this hypothesis. People who engaged actively in searching and pursuing of new goals did not seem to experience a positive change in well-being.

Earlier, mainly cross-sectional studies indicated that goal re-engagement is associated with purpose in life and positive affect (Dunne et al., 2011). Wrosch et al. (2003b) researched the association between goal re-engagement and well-being, too. They document findings which show that goal re-engagement is associated with experiences of a more meaningful life and more satisfaction with participation. The findings of Arends et al. (in press) support these findings; their research found associations between this strategy and purpose in life and satisfaction with participation as well, even though not of great significance. The present study examined the change in successful adaptation to rheumatoid arthritis in a longitudinal research design. It was found that

higher levels of goal re-engagement do not contribute to a positive change in adaptation by means of higher levels of purpose in life, positive affect and satisfaction with participation one year later. It could be the case that actively searching and pursuing new goals can help to enhance well-being. However a further improvement does not take place, perhaps due to the remaining constant levels of goal re-engagement over the investigation period of one year. The found correlations between goal re-engagement and the factors of well-being could also be due to the fact that these factors influenced the levels of goal re-engagement and not vice versa as it was possible for goal disengagement and anxiety. Furthermore a third variable problem can be of importance here, too. In these cases it can also be thought of pain or fatigue, main symptoms of rheumatoid arthritis. Arends and her colleagues (in press) gave a possible explanation for their findings that the associations between goal re-engagement and purpose in life as well as participation were not of great significance. The relative old age of the participants, which lay averagely by 62 years of age, may have played an important role. When people age it is more likely that they have fewer opportunities than younger people. Additionally their physical health presumably declines and they have a shorter future perspective in comparison with younger adults. Due to these facts the role of actively searching and pursuing new goals may decline in importance of well-being for older adults. These deliberations are likely to have bearing on the results of the present research, too. If the importance of goal re-engagement for well-being declines for older adults, a constant level of this strategy is less likely to help to improve further in well-being. The average age of the participants of this study is 60 years, so that the named deliberations are also of importance for this sample. Additionally these considerations are supported by the fact that age was a significant predictor of change in purpose in life and positive affect.

The last hypothesis assumed that an interaction effect between goal disengagement and goal re-engagement should lead to the most successful change in adaptation to rheumatoid arthritis. Because it was supposed that goal disengagement is especially useful to manage the negative consequences associated with the occurrence of unattainable goals and goal re-engagement relates to well-being, a combination of both strategies should cover all factors of successful adaptation and in this way lead to the most effective change in adaptation. This hypothesis was not confirmed. An interaction effect was found only for the adaptation factor work participation. But this outcome should be treated with caution because of the small sample size with which the regression analysis was conducted. As rule of thumb there should be ten cases for each predictor in a regression analysis. Because the regression analysis for work participation was conducted with much fewer cases than advised (28 instead of at least 80 cases) the explained variance of the model could get overestimated. The finding that no other interaction effects were significant may be due to the fact that the main effects of most strategies by themselves were not significant, either. Although it

cannot be ruled out that an interaction effect is significant while the main effects are not, this outcome is less likely.

To sum up it can be said that the goal management strategies in this study had few influence on the change of successful adaptation of rheumatoid arthritis patients to their chronic disease when they are confronted with unattainable goals. Only higher levels of goal disengagement were related to lower levels of depression one year later. Furthermore an interaction effect was found only for the adaptation factor work participation, which was however measured with a small sample size. All things considered a combination of both strategies did not enhance a positive change in adaptation to rheumatoid arthritis over one year.

This study was the first study which examined the success of goal disengagement and goal re-engagement in the change of adjustment to rheumatoid arthritis based on longitudinal data. Furthermore it made use of several facets of adaptation, encompassing the absence of depression and anxiety as well as the presence of aspects of well being, namely purpose in life, positive affect and satisfaction with participation. The use of the longitudinal research design, which was used to make changes in the adaptation visible and the considerable number of factors of adaptation to rheumatoid arthritis alone set this study apart from earlier studies. Nevertheless the duration of one year can be seen as short time for a longitudinal study. Usually spoken a longitudinal study follows the participants over a long period of time. This can take up several years or even several decades (e. g. Brandtstädter & Rothermund, 2002; Dunne et al., 2011). In comparison with these periods of time one year seems to be relatively short. Still the present study can be seen as an important step to clarify the role of the goal management strategies in relation to a change in successful adaptation. A longitudinal study design aims to appreciate underlying processes that play a role concerning that relation. But yet more longitudinal research is needed to bring to light these relationships more pronounced.

An advantage of this study was the sample size of 181 patients with rheumatoid arthritis. This relatively big sample size was possible because of the quite simple structure of the questionnaires and their mostly straightforward answering categories. Because of this it was possible to analyze a relatively large number of data in a yet efficient way and to obtain useful and representational findings. Nevertheless the sample size for the adaptation factor work participation was much smaller. As mentioned earlier this small sample size makes the analysis with this factor less reliable. It may be due to this small sample size that an unexpected finding was obtained. It was found that higher levels of goal disengagement were related to higher levels of satisfaction with work participation one year later. This means that goal disengagement had a relation with a factor of well-being, although it was supposed that it is useful for the factors of distress. But it is worth to mention that work disability is a common outcome of rheumatoid arthritis (de Croon et al., 2004). Sooner or

later a lot of patients who have this chronic disease are not longer able to pursue their profession any longer. The average disease duration of 14 years in this sample makes an incapacity for work reasonable due to the fact the functional impairments worsen gradually from pathology to disability within only few years (Katz et al., 2006; Scott et al., 2005). Furthermore the average age of this sample was 60 years, and may thus contain several people who are already retired. These aspects of the fairly large study sample made a fewer number of participants who work unavoidable.

Although a relatively comprehensive questionnaire was possible because of the easy to answer questions, some variables were assessed with quite few items. The PIL for example encompasses five items and the GAS ten items. For the latter it is to mention that the ten items are subdivided in two scales, measuring the two goal management strategies. The subscale of re-engagement consists of six, the subscale of goal disengagement even of only four items. Beyond that the goal disengagement subscale measures the two different aspects of this strategy – the reduction of effort and the relinquishment of commitment towards a goal. This means that this subscale measures a behavioral as well as a mental side of disengagement, thus leaving just two questions for each aspect (Wrosch et al., 2003b). This numbers of items seem relatively small for the fundamental role the goal management strategies play in this study. This problematic aspect finds also expression in the poor to questionable Cronbach's alphas of .52 to .65 for the disengagement scale. A contributing factor might be the fact that the originally English scale was translated into Dutch, although the problem was tried to be solved by careful forward / backward translation (Arends et al., in press). Nevertheless there is no other instrument known which measures these strategies more comprehensively. Yet earlier studies revealed Cronbach's alphas of .76 to .84 (Wrosch et al., 2003a; Neter et al. 2009), thus reaching acceptable to good levels. All in all it is to say that the results of the present study must be considered in relation to the low values of Cronbach's alpha for the disengagement scale.

Another aspect related with the filling in of questionnaires is the time of filling them in. Rheumatoid arthritis is a chronic disease which occurs in recurrent attacks. The attacks are characterized by pain and difficulties in movement. The time between the attacks is more quite for the patients (Reumafonds, n. d.). There was no possibility to figure out patients who are in an attack of their disease rather than in a calmer period. This fact of course of disease may have had influence on the answers of the participants. Even so the answers were relatively stable over the three measurements. This can indicate that the inconsistent course of disease did not have much influence on the filling in of the questionnaires.

Participants could not only be not differentiated by their course of disease but it was also not possible to differentiate between different kinds of goals. The present study measured only a general capacity to adjust to unattainable goals, not the specific goals. But some goals are more threatened

than other goals for rheumatoid arthritis patients. To attend the birthday party of a good friend is more likely to be realized than the trip of the lifetime to Africa, for example. This aspect probably influenced the answers of the participants on the questionnaires.

Overall, the study's findings have important implications for further research in the area of rheumatoid arthritis and the adjustment of goals. Although this research did not result in outcomes that have direct implication for practice, it did nevertheless some pioneering work. It was the first known research which assessed the success of the goal management strategies goal disengagement and goal re-engagement in the change of adaptation to rheumatoid arthritis with several factors of adaptation in a longitudinal design.

Research is always a process, depending on already known aspects and building up on them. Future research can make reference to this study and extend the knowledge about goal management strategies and their relation to a change in successful adaptation to rheumatoid arthritis. First of all further longitudinal studies could make use of a longer investigation period, a main consideration of the present study. Furthermore it would be useful to get more insight into the specific goals of the patients and how this influences the goal adjustment and adaptation process. This could for example be done with a different design than a questionnaire study. A sort of diary or logbook may be a possibility. With a diary participants are not forced to choose one of the possible answering categories but can freely write down their thoughts, feelings etc. surrounding a certain topic. This can help to differentiate between different goals but also between attacks and calmer periods of the course of disease, because it is individually. Moreover a diary design can help to get a better understanding of the underlying processes. Participants can write a diary entry every week for example. Additionally they can make entries if something special happens, e.g. a particular good or bad day. In this way the changes can be portrayed more pronounced. But of course is this type of study less easily to analyze and because of this fewer patients could probably be approached.

Last but not least it would be possible to integrate not just the goal management strategies goal disengagement and goal re-engagement in further research but also to include the strategies accommodation and assimilation (Brandtstädter & Renner, 1990; Brandtstädter & Rothermund, 2002). These encompass other possibilities of goal adjustment and may also play an important role in the change of adaptation to rheumatoid arthritis.

Future research can be capable of assessing the relation between goal management strategies and the change in adaptation more pronounced. And this can have important practical implications. When this relation is more clearly better intervention programs, which intend to improve the adaptation to rheumatoid arthritis, can be investigated. And this is the main aim of this work – to help people with a chronic disease to improve in adaptation and to live a satisfied life.

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Appendix

Questionnaire Measurement 1

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Leven met reuma en het aanpassen van belangrijke persoonlijke doelen

LEVEN MET REUMA EN HET AANPASSEN VAN BELANGRIJKE PERSOONLIJKE DOELEN

Vragenlijst nummer 1
Najaar 2010

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Anonimiteit
U vult deze lijst anoniem in. Dit houdt in dat de antwoorden die u geeft in deze vragenlijst niet aan uw naam of adresgegevens worden gekoppeld. Uw patiëntnummer gebruiken we om deze lijst aan de volgende vragenlijsten te kunnen koppelen. Controleert u alstublieft of onderstaand nummer uw patiëntnummer is. U vindt uw patiëntnummer op het ponskaartje van het ziekenhuis.

Wat is uw patiëntnummer?

Met het oog op het vervolg van deze vragenlijst over 6 en 12 maanden, zou ik graag de mogelijkheid hebben om telefonisch of per email contact met u op te nemen. Als u hiermee akkoord gaat, vult u dan hieronder alstublieft uw gegevens in.

Wat is uw emailadres?

Wat is uw telefoonnummer?

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1. Op welke datum vult u deze vragenlijst in?

☐☐ - ☐☐ - ☐☐☐☐

2. Wat is uw geboortedatum?

☐☐ - ☐☐ - ☐☐☐☐

3. Wat is uw geslacht?
   - ☐ man
   - ☐ vrouw

4. Wat is uw burgerlijke staat?
   - ☐ ongehuwd / niet samenwonend
   - ☐ ongehuwd/ samenwonend
   - ☐ gehuwd
   - ☐ weduwe/ weduwnaar
   - ☐ gescheiden

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

6. Wat is de beste omschrijving van uw huidige situatie? (Wilt u één antwoord geven?)
   - ☐ fulltime werk
   - ☐ parttime werk
   - ☐ huishouden
   - ☐ school of studie
   - ☐ werkloos
   - ☐ arbeidsongeschikt (WAO/WIA)
   - ☐ gepensioneerd (AOW, VUT)

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7. Welke vorm(en) van reuma heeft u?

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

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

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De volgende uitspraken hebben betrekking op situaties waarin men wensen, doelen of plannen niet zo kan realiseren zoals men dat graag zou willen. Kleur het hokje in van het antwoord dat aangeeft in hoeverre u het eens bent met de uitspraak. Denk niet te lang na, maar kies het antwoord dat spontaan in u opkomt.

	Geheel mee oneens	**Mee oneens**	**Neutraal**	**Mee eens**	**Geheel mee eens**
1) Wanneer ik ergens op vastloop, vind ik het moeilijk een andere aanpak te kiezen.	☐	☐	☐	☐	☐
2) Hoe moeilijker een doel te bereiken is, hoe aantrekkelijker ik het vind.	☐	☐	☐	☐	☐
3) Ik kan erg halsstarrig zijn in het nastreven van mijn doelen.	☐	☐	☐	☐	☐
4) Zelfs in de grootste tegenslagen zie ik vaak nog iets positiefs.	☐	☐	☐	☐	☐
5) Wanneer ik tegen problemen aanloop, span ik me gewoonlijk meer in.	☐	☐	☐	☐	☐
6) Om teleurstellingen te voorkomen, stel ik mijn doelen niet te hoog.	☐	☐	☐	☐	☐
7) Ook in schijnbaar uitzichtloze situaties blijf ik vechten om mijn doel te bereiken.	☐	☐	☐	☐	☐
8) Zelfs wanneer iets behoorlijk fout loopt, zie ik toch ergens een lichtpuntje.	☐	☐	☐	☐	☐
9) Ik verlies meestal mijn interesse voor zaken waar anderen beter in zijn.	☐	☐	☐	☐	☐
10) Ik vind het makkelijk om van een wens af te zien als deze moeilijk te vervullen lijkt.	☐	☐	☐	☐	☐

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	Geheel mee oneens	Mee oneens	Neutraal	Mee eens	Geheel mee eens
11) Wanneer ik tegen grote problemen aanloop, zoek ik liever een nieuw doel.	☐	☐	☐	☐	☐
12) Het leven is veel aangenamer, als ik er niet te veel van verwacht.	☐	☐	☐	☐	☐
13) Ik breng mijzelf in de problemen doordat ik hoge eisen stel.	☐	☐	☐	☐	☐
14) Als ik lang vergeefs met een probleem bezig geweest ben, merk ik vaak dat ik eigenlijk ook goed zonder oplossing kan leven.	☐	☐	☐	☐	☐
15) Over het algemeen ben ik niet erg lang van slag over een gemiste kans.	☐	☐	☐	☐	☐
16) Ik kan mij vrij goed aan veranderde omstandigheden of plannen aanpassen.	☐	☐	☐	☐	☐
17) Ik kan bijna overal iets positiefs in zien, zelfs wanneer ik iets wat me dierbaar is moet opgeven.	☐	☐	☐	☐	☐
18) Ik vermijd het om mij met problemen bezig te houden waarvoor ik geen oplossing heb.	☐	☐	☐	☐	☐
19) Over het algemeen ken ik mijn eigen grenzen.	☐	☐	☐	☐	☐
20) Wanneer ik een doel niet kan bereiken, verander ik liever mijn doel dan maar te blijven proberen.	☐	☐	☐	☐	☐
21) Na een grote tegenslag richt ik me snel op nieuwe taken.	☐	☐	☐	☐	☐
22) Ik sluit wel eens mijn ogen voor grote problemen.	☐	☐	☐	☐	☐

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	Geheel mee oneens	Mee oneens	Neutraal	Mee eens	Geheel mee eens
23) Als ik niet gemakkelijk krijg wat ik wil, blijf ik het geduldig proberen.	☐	☐	☐	☐	☐
24) Bij een teleurstelling herinner ik mijzelf eraan dat andere dingen in het leven net zo belangrijk zijn.	☐	☐	☐	☐	☐
25) Ook als alles mis lijkt te gaan, blijf ik meestal positief.	☐	☐	☐	☐	☐
26) Nederlagen kan ik moeilijk accepteren.	☐	☐	☐	☐	☐
27) Zelfs als alles uitzichtloos lijkt, probeer ik nog de situatie onder controle te krijgen.	☐	☐	☐	☐	☐
28) Wanneer ik eenmaal iets in mijn hoofd heb gezet, laat ik me daar zelfs niet door grote moeilijkheden vanaf brengen.	☐	☐	☐	☐	☐
29) Wanneer ik in ernstige problemen zit, vraag ik me meteen af hoe ik het beste van de situatie kan maken.	☐	☐	☐	☐	☐
30) Ik zal alleen dan echt tevreden zijn, wanneer alles precies is zoals ik het wil.	☐	☐	☐	☐	☐

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Leven met reuma en het aanpassen van belangrijke persoonlijke doelen

Gedurende het leven kunnen mensen niet altijd bereiken wat ze zouden willen bereiken. Mensen worden soms gedwongen om te stoppen met het nastreven van doelen die ze zichzelf in het leven hebben gesteld. We willen weten **hoe u normaal gesproken zou reageren** als u dit zou overkomen. Kleur het hokje in dat aangeeft in welke mate u het eens of oneens bent met de onderstaande stellingen.

Als ik zou moeten stoppen met het nastreven van een belangrijk doel in mijn leven...

	Geheel mee oneens	**Mee oneens**	**Neutraal**	**Mee eens**	**Geheel mee eens**
1) ...verlaag ik gemakkelijk mijn inspanningen om het doel te bereiken.	☐	☐	☐	☐	☐
2) ...overtuig ik mezelf ervan dat ik andere belangrijke doelen heb om na te streven.	☐	☐	☐	☐	☐
3) ...houd ik toch nog lang aan dat doel vast; ik kan het niet loslaten.	☐	☐	☐	☐	☐
4) ...ga ik aan andere doelen werken.	☐	☐	☐	☐	☐
5) ...bedenk ik andere nieuwe doelen die ik kan nastreven.	☐	☐	☐	☐	☐
6) ...vind ik het moeilijk om dit doel niet meer na te streven.	☐	☐	☐	☐	☐
7) ...zoek ik andere betekenisvolle doelen.	☐	☐	☐	☐	☐
8) ...vind ik het makkelijk om dit doel los te laten en er niet meer aan te denken.	☐	☐	☐	☐	☐
9) ...zeg ik tegen mezelf dat ik nog genoeg andere nieuwe doelen heb waarop ik me kan richten.	☐	☐	☐	☐	☐
10)...zet ik me in voor andere betekenisvolle doelen.	☐	☐	☐	☐	☐

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We willen nu graag weten hoe u denkt over uw eigen mogelijkheden om zo goed mogelijk met uw ziekte om te gaan. Wilt u bij de volgende uitspraken aangeven in hoeverre u het met deze uitspraken eens bent?

	Geheel mee oneens	**Mee oneens**	**Neutraal**	**Mee eens**	**Geheel mee eens**
1) Ik ben tevreden over mijn eigen mogelijkheden om de pijn van mijn reumatische aandoening te beheersen.	☐	☐	☐	☐	☐
2) Bij pijn en stijfheid door mijn reumatische aandoening kan ik mijn dagelijkse bezigheden gewoon blijven uitvoeren.	☐	☐	☐	☐	☐
3) Ik ben er zeker van dat ik kan slapen ondanks de pijn van mijn reumatische aandoening.	☐	☐	☐	☐	☐
4) Ik ben er zeker van dat ik de pijn als gevolg van mijn reumatische aandoening behoorlijk kan verminderen zonder extra medicijnen te gebruiken.	☐	☐	☐	☐	☐
5) Ik ben er zeker van dat ik de pijn door mijn reumatische aandoening tijdens mijn dagelijkse bezigheden goed aankan.	☐	☐	☐	☐	☐
6) Ik ben tevreden over mijn eigen mogelijkheden om zelf dagelijkse bezigheden uit te voeren.	☐	☐	☐	☐	☐
7) Ik ben er zeker van dat ik mijn vermoeidheid kan beheersen.	☐	☐	☐	☐	☐

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	Geheel mee oneens	**Mee oneens**	**Neutraal**	**Mee eens**	**Geheel mee eens**
8) Ik ben er zeker van dat ik mijn bezigheden zo kan regelen dat mijn reumatische aandoening er niet door wordt verergerd.	☐	☐	☐	☐	☐
9) Ik ben er zeker van dat ik me er zelf weer bovenop kan helpen als ik me een beetje somber voel.	☐	☐	☐	☐	☐
10)Ik ben er zeker van dat ik mijn reumatische aandoening zodanig kan beheersen dat ik kan doen wat ik leuk vind.	☐	☐	☐	☐	☐
11)Ik ben er zeker van dat ik de frustraties die ik door mijn reumatische aandoening ondervind, aankan.	☐	☐	☐	☐	☐

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

1) Ik voel me gespannen:
- ☐ Meestal
- ☐ Vaak
- ☐ Af en toe, soms
- ☐ Helemaal niet

2) Ik geniet nog steeds van de dingen waar ik vroeger van genoot:
- ☐ Zeker zo veel
- ☐ Niet zoveel als vroeger
- ☐ Weinig
- ☐ Haast helemaal niet

3) Ik krijg een soort angstgevoel alsof er elk moment iets vreselijks zal gebeuren:
- ☐ Heel zeker en vrij erg
- ☐ Ja, maar niet zo erg
- ☐ Een beetje, maar ik maak me er geen zorgen over
- ☐ Helemaal niet

4) Ik kan lachen en de dingen van de vrolijke kant zien:
- ☐ Net zoveel als vroeger
- ☐ Niet zo goed als vroeger
- ☐ Beslist niet zoveel als vroeger
- ☐ Helemaal niet

5) Ik maak me vaak ongerust:
- ☐ Heel erg vaak
- ☐ Vaak
- ☐ Af en toe maar niet te vaak
- ☐ Alleen soms

6) Ik voel me opgewekt:
- ☐ Helemaal niet
- ☐ Niet vaak
- ☐ Soms
- ☐ Meestal

7) Ik kan rustig zitten en me ontspannen:
- ☐ Zeker
- ☐ Meestal
- ☐ Niet vaak
- ☐ Helemaal niet

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8) Ik voel me alsof alles moeizamer gaat:
- ☐ Bijna altijd
- ☐ Heel vaak
- ☐ Soms
- ☐ Helemaal niet

9) Ik krijg een soort benauwd, gespannen gevoel in mijn maag:
- ☐ Helemaal niet
- ☐ Soms
- ☐ Vrij vaak
- ☐ Heel vaak

10) Ik heb geen interesse meer in mijn uiterlijk:
- ☐ Zeker
- ☐ Niet meer zoveel als ik zou moeten
- ☐ Waarschijnlijk niet zoveel
- ☐ Evenveel interesse als vroeger

11) Ik voel me rusteloos en voel dat ik iets te doen moet hebben:
- ☐ Heel erg
- ☐ Tamelijk veel Niet
- ☐ erg veel
- ☐ Helemaal niet

12) Ik verheug me van tevoren al op dingen:
- ☐ Net zoveel als vroeger
- ☐ Een beetje minder dan vroeger
- ☐ Zeker minder dan vroeger
- ☐ Bijna nooit

13) Ik krijg plotseling gevoelens van panische angst:
- ☐ Zeer vaak
- ☐ Tamelijk vaak Niet
- ☐ erg vaak
- ☐ Helemaal niet

14) Ik kan van een goed boek genieten, of van een radio- of televisieprogramma:
- ☐ Vaak
- ☐ Soms
- ☐ Niet vaak
- ☐ Heel zelden

15) Neemt u door een arts voorgeschreven medicijnen om uw stemming te verbeteren?
- ☐ Ja
- ☐ Nee

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Bij de volgende uitspraken gaat het erom hoe u **uw leven als geheel** ervaart.
Wilt u alstublieft het vakje van het antwoord dat het meest bij u past, inkleuren?

	Geheel mee oneens	**Mee oneens**	**Neutraal**	**Mee eens**	**Geheel mee eens**
1) Ik voel dat mijn leven een richting en een doel heeft.	☐	☐	☐	☐	☐
2) Mijn dagelijkse activiteiten lijken mij vaak triviaal en onbelangrijk.	☐	☐	☐	☐	☐
3) Ik heb geen duidelijk gevoel over wat ik probeer te bereiken in het leven.	☐	☐	☐	☐	☐
4) Ik geniet ervan om plannen te maken en te werken aan de realisering ervan.	☐	☐	☐	☐	☐
5) Sommige mensen gaan doelloos door het leven, maar ik niet.	☐	☐	☐	☐	☐
6) Mijn dagelijkse activiteiten zijn voor mij een bron van veel genoegen en voldoening.	☐	☐	☐	☐	☐

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Deze vragenlijst bestaat uit een aantal woorden die verschillende gevoelens en emoties beschrijven. Kleur alstublieft het vakje in wat weergeeft in hoeverre u zich zo gevoeld hebt in de **afgelopen week**.

	Nauwe-lijks of helemaal niet	**Een beetje**	**Matig**	**Best veel**	**Inmtaetrke s**
	☐	☐	☐	☐	☐ e
1) Geïnteresseerd	☐	☐	☐	☐	☐
2) Uitgelaten	☐	☐	☐	☐	☐
3) Sterk	☐	☐	☐	☐	☐
4) Enthousiast	☐	☐	☐	☐	☐
5) Trots	☐	☐	☐	☐	☐
6) Alert	☐	☐	☐	☐	☐
7) Geïnspireerd	☐	☐	☐	☐	☐
8) Vastberaden	☐	☐	☐	☐	☐
9) Aandachtig	☐	☐	☐	☐	☐
10) Actief					

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In de deze vragenlijst worden een aantal vragen gesteld over dagelijkse bezigheden. Het doel van deze vragenlijst is om een beeld te krijgen van de manier waarop uw gezondheid de mogelijkheden beïnvloedt om het leven te leiden dat u wilt, en hoe u dit beleeft en beoordeelt.

Bij de beantwoording van de vragen gaat het uitsluitend om uw mening en uw ervaringen. Er zijn geen goede of foute antwoorden; het gaat erom dat u het antwoord geeft dat volgens u het beste bij uw situatie past.

Bij elke vraag selecteert u steeds één antwoord. Ook wanneer u een vraag onbelangrijk vindt of hierover geen mening heeft, vragen wij u het antwoord te selecteren dat het beste bij uw situatie past. Wanneer u twijfelt, kies dan het antwoord dat het dichtst in de buurt komt van wat u denkt.

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Bezigheden en taken in en om het huis

De volgende vragen gaan over de bezigheden en verantwoordelijkheden die u thuis hebt. Hierbij kunt u o.a. denken aan de verzorging en opvoeding van kinderen, huisdieren, huishoudelijke werkzaamheden en onderhoud van de tuin. Het gaat er om in hoeverre *u* kunt bepalen wanneer en hoe iets gebeurt, ook als u het niet zelf doet, daarom staat het woord 'laten' in sommige vragen tussen haakjes.

	Slecht	Matig	Redelijk	Goed	Zeer goed
1) Mijn bijdrage aan de taken in en om het huis ***zoals*** ik dat wil, is:	☐	☐	☐	☐	☐
2) Het (laten) doen van licht huishoudelijk werk, (bijvoorbeeld koffie of thee zetten) ***zoals*** ik het wil, gaat:	☐	☐	☐	☐	☐
3) Het (laten) doen van zwaarder huishoudelijk werk (bijvoorbeeld schoonmaken) ***zoals*** ik het wil, gaat:	☐	☐	☐	☐	☐
4) Het (laten) doen van huishoudelijke taken ***wanneer*** ik dat wil, gaat:	☐	☐	☐	☐	☐
5) Het (laten) doen van klusjes en onderhoud van huis en tuin ***zoals*** ik het wil, gaat:	☐	☐	☐	☐	☐
6) De mogelijkheid om in huis de rol te vervullen die bij mij hoort, is:	☐	☐	☐	☐	☐

Geldbesteding

In deze vraag gaat het erom of uw gezondheid of beperking van invloed is op de besteding van uw inkomen of zakgeld.

	Slecht	Matig	Redelijk	Goed	Zeer goed
7) De mogelijkheid om mijn geld te besteden ***zoals*** ik het wil, is:	☐	☐	☐	☐	☐

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Sociale contacten en relaties

De volgende vragen gaan over de kwaliteit en frequentie van uw sociale contacten. Het kan zijn dat door uw gezondheid of beperking sociale contacten anders verlopen of minder vaak voorkomen.
In de vragen 10 en 12 wordt gesproken van '*respect*'. Met *respect* wordt bedoeld de mate waarin anderen u correct en beleeft behandelen.

	Slecht	Matig	Redelijk	Goed	Zeer goed
8) De mogelijkheid tot een ***gelijkwaardig*** gesprek met de mensen die me dierbaar zijn, is:	☐	☐	☐	☐	☐
9) De omgang met de mensen die me dierbaar zijn, is:	☐	☐	☐	☐	☐
10)Het respect dat ik ontvang van mensen die me dierbaar zijn, is:	☐	☐	☐	☐	☐
11)De omgang met mensen die ik minder goed ken, is:	☐	☐	☐	☐	☐
12)Het respect dat ik ontvang van mensen die ik minder goed ken, is:	☐	☐	☐	☐	☐
13)De mogelijkheid tot intimiteit, zoals ik dat wil, is:	☐	☐	☐	☐	☐

Anderen helpen of steunen

Deze vraag gaat over uw mogelijkheden om anderen te helpen of te steunen. Daarbij kunt u denken aan familie, vrienden, buren of kennissen, maar ook aan de vereniging of organisatie waar u misschien lid van bent.

	Slecht	Matig	Redelijk	Goed	Zeer goed
14)De mogelijkheid om mensen te helpen of steunen die me nodig hebben, is:	☐	☐	☐	☐	☐

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Betaald werk of vrijwilligerswerk

Dan nu een vraag over werk (betaald of vrijwilligerswerk). We willen graag uw mening horen over uw mogelijkheid om het werk van uw keuze te vinden of te behouden, ook als dit onderwerp voor u op dit moment niet zo relevant is.

	Slecht	Matig	Redelijk	Goed	Zeer goed
15) De mogelijkheid om het betaalde werk of vrijwilligerswerk te doen dat ik wil, is:	☐	☐	☐	☐	☐

Wanneer u op dit moment geen betaalde baan heeft en geen vrijwilligerswerk doet, kunt u verder gaan met vraag 20. Wanneer u wel werk heeft of door ziekte tijdelijk niet werkt, vragen wij u om de volgende vragen wel in te vullen.

	Slecht	Matig	Redelijk	Goed	Zeer goed
16) De mogelijkheid om mijn werk uit te voeren ***zoals*** ik het wil is:	☐	☐	☐	☐	☐
17) Het contact met collega's is:	☐	☐	☐	☐	☐
18) De mogelijkheid om de positie te bereiken of te handhaven die ik wil, is:	☐	☐	☐	☐	☐
19) De mogelijkheid om van functie of werkgever te veranderen, is:	☐	☐	☐	☐	☐

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Onderwijs, cursussen en opleiding
De volgende vraag gaat over de invloed van uw gezondheid of beperking op de mogelijkheid om de opleiding of cursus van uw keuze te (blijven) volgen. Wanneer u niet de wens heeft om een opleiding of cursus te volgen, vult u 'niet van toepassing' in.

	Slecht	Matig	Redelijk	Goed	Zeer goed
20) De mogelijkheid om de opleiding of cursus van mijn keuze te (blijven) volgen, is:	☐	☐	☐	☐	☐

Niet van toepassing: ☐

Mobiliteit: gaan en staan waar en wanneer u wilt
Nu willen we u een aantal vragen stellen over mobiliteit: de mogelijkheid om te gaan en staan waar en wanneer u wilt buitenshuis. Het gaat er in deze vragen vooral om of u zelf kunt bepalen waar u in uw (vrije) tijd naar toe gaat en wanneer u dat doet en hoe lang.

	Slecht	Matig	Redelijk	Goed	Zeer goed
21) Het bezoeken van buren, vrienden en kennissen ***wanneer*** ik dat wil, gaat:	☐	☐	☐	☐	☐
22) Het maken van uitstapjes of een (vakantie)-reis ***zoals*** ik dat wil, gaat:	☐	☐	☐	☐	☐
23) De mogelijkheid om mijn vrije tijd te besteden ***zoals*** ik het wil, is:	☐	☐	☐	☐	☐
24) De frequentie waarmee ik mensen zie, is:	☐	☐	☐	☐	☐

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Samenvattend
In deze vragenlijst heeft u vragen beantwoord die te maken hebben met de gevolgen van uw gezondheid of beperking voor uw persoonlijke, sociale en maatschappelijke leven. Wilt u nog eens in het algemeen aangeven of u vindt dat u zelf voldoende kunt bepalen wat u wilt (laten) doen?

	Slecht	**Matig**	**Redelijk**	**Goed**	**Zeer goed**
25) Mijn mogelijkheid om te leven op de manier zoals ik het wil, is:	☐	☐	☐	☐	☐

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De volgende vragen gaan over de invloed van uw ziekte op het functioneren in het dagelijks leven. Kruis alstublieft het antwoord aan dat het best beschrijft wat u meestal kon doen in de **afgelopen week**.

AANKLEDEN & VERZORGING	**zonder enige moeite**	**met enige moeite**	**met veel moeite**	**onmogelijk uit te voeren**
1) Kunt u zichzelf aankleden, inclusief veters strikken en knopen dichtmaken?	☐	☐	☐	☐
2) Kunt u uw haren wassen?	☐	☐	☐	☐
OPSTAAN				
3) Kunt u opstaan vanuit een rechte stoel?	☐	☐	☐	☐
4) Kunt u in en uit bed komen?	☐	☐	☐	☐
ETEN				
5) Kunt u vlees snijden?	☐	☐	☐	☐
6) Kunt u een vol kopje of glas naar de mond brengen?	☐	☐	☐	☐
7) Kunt u een nieuw pak melk openen?	☐	☐	☐	☐
LOPEN				
8) Kunt u buitenshuis op een vlakke grond wandelen?	☐	☐	☐	☐
9) Kunt u vijf traptreden opklimmen?	☐	☐	☐	☐

Kruis aan welke HULPMIDDELEN u normaal gebruikt voor de bovenstaande activiteiten:

☐ Wandelstok
☐ Rollator / looprekje
☐ Krukken
☐ Rolstoel
☐ Hulpmiddelen, gebruikt bij het aankleden (knoophaak, ritssluiting-trekker, lange-steel schoenlepel, etc.)
☐ Speciale of aangepaste hulpmiddelen bij eten of drinken
☐ Speciale of aangepaste stoel
☐ Overige hulpmiddelen

Kruis elke categorie aan waarvoor normaal HULP VAN ANDEREN nodig heeft:

☐ Aankleden / verzorging
☐ Opstaan
☐ Eten
☐ Lopen

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

	zonder enige moeite	**met enige moeite**	**met veel moeite**	**onmogelijk uit te voeren**
HYGIËNE				
10)Kunt u zelf uw lichaam wassen en afdrogen?	☐	☐	☐	☐
11)Kunt u in en uit bad komen?	☐	☐	☐	☐
12)Kunt u op en van het toilet komen?	☐	☐	☐	☐
REIKEN				
13)Kunt u iets van 2,5 kg (bijvoorbeeld een zak aardappelen of rijst) van net boven uw hoofd pakken?	☐	☐	☐	☐
14)Kunt u voorover buigen om kleren van de vloer op te rapen?	☐	☐	☐	☐
GRIJPKRACHT				
15)Kunt u auto-portieren openen?	☐	☐	☐	☐
16)Kunt u deksels van potten, die al eens geopend zijn, losdraaien?	☐	☐	☐	☐
17)Kunt u een kraan open- en dichtdraaien?	☐	☐	☐	☐
ACTIVITEITEN				
18)Kunt u boodschappen doen en winkelen?	☐	☐	☐	☐
19)Kunt u in en uit een auto komen?	☐	☐	☐	☐
20)Kunt u klusssen doen, zoals stofzuigen of tuinieren?	☐	☐	☐	☐

Kruis aan welke HULPMIDDELEN u normaal gebruikt voor de bovenstaande activiteiten:

☐ Verhoogd toilet
☐ Zitje in de badkuip
☐ Potdeksel-opener
☐ Badkuip-muurstang
☐ Lange-steel hulpmiddelen om iets te bereiken
☐ Lange-steel hulpmiddelen in de badkamer
☐ Overige hulpmiddelen

Kruis elke categorie aan waarvoor u normaal HULP VAN ANDEREN nodig heeft:

☐ Hygiëne
☐ Naar voorwerpen reiken
☐ Voorwerpen pakken en openen
☐ Boodschappen doen en klussen

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1) Vult u nu alstublieft het vakje in van het getal wat aangeeft hoeveel pijn u had in de afgelopen 7 dagen als gevolg van uw aandoening.

helemaal geen pijn ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 **ondraaglijke pijn**

2) Geef op onderstaande lijn uw mate van vermoeidheid aan, gemiddeld genomen over de afgelopen 7 dagen.
Wilt u dit aangeven door een verticaal streepje (I) *te zetten op onderstaande lijn?*

geen vermoeid-heid _____ **totaal uitgeput**

3) Geef op onderstaande lijn aan hoeveel effect vermoeidheid de afgelopen 7 dagen op uw leven heeft gehad.
Wilt u dit aangeven door een verticaal streepje (I) *te zetten op onderstaande lijn?*

geen effect _____ **heel veel effect**

4) Geef op onderstaande lijn aan hoe goed u de laatste 7 dagen met vermoeidheid bent omgegaan.
Wilt u dit aangeven door een verticaal streepje (I) *te zetten op onderstaande lijn?*

helemaal niet goed _____ **zeer goed**

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Kruis **elke** aandoening aan waarvoor u het **afgelopen jaar** onder behandeling bent geweest bij een huisarts of medisch specialist.

- ☐ Infectieziekten (bijv. ziekte van lyme, malaria, hepatitis, AIDS/HIV)
- ☐ Kwaadaardige aandoening of kanker
- ☐ Bloedziekte of aandoening afweersysteem (bijv. stollingsstoornis, sikkelcelanemie)
- ☐ Stofwisselingsaandoening (bijv. diabetes, aandoening aan de (bij)schildklier)
- ☐ Psychische aandoening (bijv. depressie, angststoornis)
- ☐ Aandoening van het zenuwstelsel (bijv. epilepsie, Parkinson, M.S., hernia)
- ☐ Aandoening van zintuigen (gezichts-of gehoorproblemen)
- ☐ Aandoening van het hart- of vaatstelsel (bijv. angina pectoris, hartinfarct)
- ☐ Aandoening van het ademhalingsstelsel (bijv. astma, longemfyseem, COPD)
- ☐ Aandoening van het spijsverteringsstelsel (maag-, darm-, of leverproblemen)
- ☐ Aandoening van de huid (bijv. eczeem, psoriasis)
- ☐ Aandoening van urinewegen of geslachtsorganen (bijv. nieraandoening)
- ☐ Allergie (bijv. hooikoorts, allergie voor huisstofmijt, voedselallergie)
- ☐ Letsel, vergiftiging of gevolgen na een ongeluk/ongeval
- ☐ Chronische vermoeidheid (bijv C.V.S. of M.E.)
- ☐ Andere hiervoor niet genoemde aandoening(en)

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Hartelijk dank voor het invullen van de vragenlijst. Wilt u nog even controleren of u geen vragen vergeten bent?

Wilt u de ingevulde vragenlijst samen met het ondertekende toestemmingsformulier terugsturen in de antwoordenvelop?

Vriendelijke groet,

Roos Arends

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