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## Functional ability, social support and quality of life

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*Document Version*

Publisher's PDF, also known as Version of record

*Publication date:*

2000

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Doeglas, D. M. (2000). *Functional ability, social support and quality of life: a longitudinal study in patients with early rheumatoid arthritis*. [Thesis fully internal (DIV), University of Groningen]. s.n.

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# 7 Functional ability, social support and depression in rheumatoid arthritis

(Dirk Doeglas, Theo Suurmeijer, Wim van den Heuvel, Boudien Krol, Martin van Rijswijk, Miek van Leeuwen, and Robbert Sanderman)

## 7.1 Introduction

Rheumatoid Arthritis (RA) is, like most chronic diseases, characterized by an unknown etiology and an unknown course and prognosis on the individual level. Particularly in recent onset cohorts, the disease has a highly variable and unpredictable course (Wolfe et al. 1991, Zeben et al. 1993, Ward 1993, Young 1995). However, sooner or later all patients with RA will be confronted with the physical consequences of the disease, i.e. a decrease in functional ability. Because of inflammation of the joints, which is the main characteristic of RA, patients are troubled, for example, by pain, stiffness, and lack of energy, and fatigue (Riemsma et al. 1998a). As a result, the joints are affected, which leads to a decrease in functional ability in a varying degree and progression. Subsequently, many difficulties will arise in the performance of tasks, like activities of daily living, or activities related to work and leisure. Because of a decrease in functional ability, patients with RA become less mobile, which will often result in qualitative and quantitative changes in social relationships. Hence, besides leading to physical limitations, RA often has social consequences as well. In addition to the physical and social consequences, also psychological problems often occur. Due to the unpredictable course of RA, patients are confronted with uncertainty, threat, and ambiguity. As a result, a decrease in self-esteem, a decline in psychological well-being, or the occurrence of depressive symptoms are commonly reported in patients with RA (Krol et al. 1994, Anderson et al. 1985, Wolfe and Hawley 1993, Eberhardt et al. 1993, Brown et al. 1989, Revenson et al. 1991, Hurwicz and Berkanovic 1993, McEvoy DeVellis 1993, Abdel-Nasser et al. 1998). Some studies reported depression (both major depressive disorder and dysthymic disorder) in more than 40% of the patients involved (Frank et al. 1988, Rimón and Laakso 1984, Wells et al. 1988). Basically, this pleads for a multi-dimensional approach of the consequences of chronic disorders. The quality of life (QoL) construct was introduced to assess and evaluate more comprehensively the outcomes or effects of (chronic) illness and medical interventions. The international World Health Organization Quality Of Life (WHOQOL) group has defined quality of life, as ‘the individuals’

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perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns' (WHOQOL 1995). In this definition, the patients' perspective on QoL is central and encompasses the personal assessment by the patient of his physical health status (e.g. physical functioning, disability) and his psychological and social functioning (e.g. mood, companionship, recreational activities). The patients' perception of his quality of life is thus 'subject-bound'. To our opinion, this conceptualization of QoL excludes the use of so-called 'objective social indicators' (e.g. employment, socio-economic status, or the use of recreational facilities), or 'objective' health-related indicators of quality of life (e.g. comorbidity, or health care utilization), which can be considered as 'necessary conditions for satisfaction and happiness' (Rogerson 1995). According to Spilker (1990) three levels of quality of life can be distinguished. The first level is the 'global' overall assessment of quality of life, which is defined as 'an individual's overall satisfaction with life, and one's general sense of personal well-being' (Taal 1997a). The second level comprises the major domains of quality of life. Often three domains are distinguished: the physical, mental and social domains, corresponding with physical health, mental health and social health (König-Zahn et al. 1993). The third level of quality of life includes specific parts of each domain. The model assumes that the variables or aspects of the lower level more or less determine the more general values at a higher level and ultimately determine the overall assessment of well-being and that the different aspects (or domains) of the quality of life concept are interrelated. The present study is on the interrelationship between functional ability, social support and depressive feelings in patients with RA. Functional ability, depressive feelings and social support are conceived as indicators of the physical, mental and social domains of quality of life respectively.

According to this conceptualization of QoL, it is assumed that a decline in functional ability, caused by the chronic disease, is related to a decline in functioning on the social and mental component of QoL. This is in line with the model of conservation of resources, which defines stress as a reaction to the environment in which there is a perceived threat of a net loss of resources. Physical illness is denoted as one of the greatest and most common stressors, because ... 'it threatens both the victim and his or her social network. The loss for the individual involves independence, social mobility, capacity to work, exposure to pain, and threat of disfigurement and death' (Hobfoll 1988, 1990). Related to this Ormel et al. (1996) found that restrictions in functional ability, as well as (to a lesser degree) coping capacity (control, competence and social support) directly mediate the impact of chronic diseases on mental health. Furthermore, Van

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Linschoten (1994) has demonstrated that changes in functional ability and changes in psychological distress (somatic symptoms) both independently affect self-rated health, and that in patients with a high(er) level of psychological distress, the relationship between the change in functional ability and the change in self-rated health is stronger.

Mostly, two main dimensions of social support are distinguished: social-emotional support and instrumental support (Thoits 1982). Different types of social support will be beneficial for different types of needs and, therefore, will have different places in the social support process (McColl and Friedland 1995). Based on empirical results, it was concluded that social-emotional support is of great importance in reducing the intensity of fear, depressive feelings and anger that may result from serious illness (Cutrona and Russell 1990). In this respect, such diseases may be conceived as a chronic strain being responsible for raised levels of stress, and should be distinguished from the number of stressful events in a certain period of time.

Social support is assumed to have a beneficial effect on health through two mechanisms (Krol et al. 1993, Vaux 1988, Cohen and Syme 1985, Sarason et al. 1990). First, social support has a main or direct effect on the well-being of individuals. People who meet warmth and affection in their relations with others, who are helped in case of need, and who have social companionship once in a while, are better off than people who are not supported in any of these ways. This lack of support is assumed to constitute strain (strain hypothesis). On the other hand, it is maintained that social support is a vulnerability factor that moderates the effect of life stress, the so-called stress reducing or buffering effect (vulnerability or buffering hypothesis). The traditional buffering hypothesis states that the impact of stress on mental health is stronger under conditions of low support than of high support (Kessler and McLeod 1985). This indirect effect implies that people who receive support in stressful situations, will be able to maintain a greater sense of security and a higher feeling of self-esteem and self-identity. This will result in lower vulnerability to negative effects stemming from these stressful situations. Thus, due to their disease, patients with RA have to cope with chronic strains. As a result of these chronic strains (stress) normal daily life is threatened, which will lead to higher level of physical distress. In this respect, De Haes (1988) describes that raised levels of depressive feelings are especially due to the disturbance of an equilibrium. After some time, a new equilibrium is probably re-established by adaptation or by social comparison of the patient. This implies that the initial raised levels of depressive feelings will diminish after some time.

In general, the concept of social support is well accepted and all

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studies succeeded in demonstrating the direct effect of social support. However, demonstrating the buffering effect of social support has appeared to be difficult. Some studies simply failed to demonstrate this effect (Felton et al. 1984, Pakenham et al. 1994, Fitzpatrick et al. 1988, Doeglas et al. 1994), while from other studies (Brown et al. 1989, Thoits 1982, Vaux 1988, Cohen and Wills 1985, Thoits 1983, Waltz et al. 1988, Lavee et a. 1985, Sarason et al. 1985, Lepore 1992, Unger et al. 1996, Kriegsman et al. 1997, Penninx et al. 1997, Komproe et al. 1997, Affleck et al. 1988), it is often unclear whether the claimed buffering effect was suggested by the results, or that the buffering effect was really demonstrated by a significant interaction term between stressor and social support. Change score studies on stress- buffering are even more scarce. At present, one other longitudinal study is known among patients with RA, in which the buffering effect of support (with pain as stressor) could not be demonstrated (Fitzpatrick et a. 1991). For this reason, the buffering effect has been criticized on its conceptualization as well as on its measurement (Vilhjalmsson 1993, LaRocco 1983, McKee and Vilhjalmsson 1986).

Although the theoretical effects of social support are generally accepted, and its dimensions are largely agreed upon, less consensus exists about what aspect of social support should be provided in case of need. Some of the providers' transactions are intended to be supportive, but it is the recipient's evaluation that determines the value in terms of satisfaction with the support provided. Actual supportive transactions and the satisfaction with the provided supportive transactions are two different aspects of the social support concept. In this respect, it was demonstrated that compared to supportive transactions, support satisfaction was more relevant in explaining health-related quality of life measures (Doeglas et al. 1996). Satisfaction is related to the gratification of recent needs (e.g. as a result of the onset of RA), while dissatisfaction, in contrast, entails either some form of emotional isolation or distressing and unsupportive social ties (Waltz et al. submitted).

This study among early RA patients focuses on two main research questions. Firstly, since this study is on early rheumatoid arthritis, an important question to be answered is how the patterns of functional ability, depressive feelings and social support develop in the first years of the disease. As a result of the presumed erratic pattern of early RA, it is expected that the mean scores on these measures will hardly change in the early phase of the disease. Furthermore it is expected that although the mean scores will not change much in time, depressive feelings will be direct-proportionally related to functional ability, i.e. low functional ability coincides with high depressive feelings, while an decrease in functional ability will correspond with an increase in depressive feelings and vice versa.

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According to De Haes (1988), the patterns may become curve-linear after some time, due to coping resources and coping behaviour, i.e. competence, social support. This implies that patients who receive more support and who are more satisfied with the support they receive, will experience less psychological distress than those patients without or with little social support (satisfaction). Therefore, the second research question concerns the direct and indirect (buffering) effect of social-emotional support on the relationship between functional ability and depressive feelings.

## 7.2 Patients and methods

### 7.2.1 *Selection of patients*

As part of the EURIDISS-project (EUropean Research on Incapacitating DIseases and Social Support 1990), patients were selected who presented symptoms corresponding to or suspected as being caused by RA. For this study, only the Dutch part of the data set was used. The criteria for inclusion of patients were: residents in the sampling areas, aged 20 to 70, diagnosis of RA according to the 1987 ARA criteria (Arnett et al. 1988), and a disease duration of 4 years or less.

Of a sample of 640 initially selected patient files, the rheumatologists successively selected 371 patients according to the 1987 ARA criteria. From this sample of 371 patients, forty patients were excluded for the following reasons: other serious incapacitating diseases, stage IV of Steinbrocker (1949) functional classes, or possible loss in follow-up (e.g. expected to move outside the sampling area). Thirty nine patients (12%) refused to participate for several reasons. The initial sample (at T1) comprised 292 patients, who were followed for three years (T2, T3, and T4). Due to loss in follow-up, at T4 268 patients with RA were left. A mean loss of 2.7% per wave of data collection, which may be considered as very low. Another four patients were lost due to missing data which left us with 264 patients with RA for our analyses. During each wave of data collection, both clinical and psychosocial data were collected. Clinical data were collected by a trained research nurse. Psychosocial data were collected by nine trained interviewers during an extensive interview (both the verbal interview and self-report questionnaires) administered at the patients' home. The medical check-up and the interview were scheduled within a fortnight. Before the study started, all patients signed a letter of informed consent. At the start of the study (at T1), the mean disease duration was 22 months (sd = 14), while the mean age of the total sample was 53 years (sd = 12); 65% women.

### 7.2.2 *Measures*

In this study three different self-report questionnaires were used to assess the physical, mental and social components of quality of life.

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In order to assess the mental component of quality of life, the depression subscale of the General Health Questionnaire (the 28 item version of the GHQ) was used. This subscale comprises 7 items. The GHQ-28 is a frequently used instrument which has proven to be valid and reliable in measuring psychological distress (Goldberg and Hillier 1979, Sanderman and Stewart 1990, Krol et al. 1994). The items have four response categories: 1) not at all, 2) no more than usual, 3) rather more than usual, and 4) much more than usual. Consequently, the score on the depression subscale ranges from 7 to 28. The higher the score on the depression subscale of the GHQ, the stronger the depressive feelings and the lower the patients' psychological well-being.

To measure the social component of quality of life, the Social Support Questionnaire for Satisfaction (SSQS) was used (Doeglas et al. 1996). The satisfaction with the social support provided was defined as the discrepancy between the actual level and the desired (or required) level of supportive transactions. The SSQS should be used together with the Social Support Questionnaire for Transactions (SSQT; Suurmeijer et al. 1995). Each item, assessing the level of transactions (in the SSQT), was directly followed by a question asking about the discrepancy between the actual and the desired number of transactions<sup>5</sup>. Both the SSQT and the SSQS distinguish between different types of social support. In the present study, the Emotional Support Satisfaction (ES-SAT) and the Social Companionship Satisfaction (SC-SAT) subscales were used. The SC-SAT consists of 5 items referring to the patient's sociable relationships or weak interpersonal ties, while the ES-SAT consists of 11 items referring to corresponding emotionally close or strong interpersonal ties. The response on the SSQS is an evaluation of the actual number of support transactions that were provided. The original response categories of the items of the SSQS run from '(much) less than I like', via 'just as much as I like', to 'more than I like'. As such, the SSQS does not form a linear scale, which is not desirable for statistical reasons. Because only a few respondents had filled out that they were provided with 'too much support', the original (four) categories were recoded into the following three categories: much less than I like (score 1); less than I like (score 2); and just as much as I like (score 3) including those who reported 'more than I like'. This latter group was considered as being provided with enough support in comparison with respondents who indicated to receive 'too less' support. The ES-SAT scores run from 11 to 33 and the SC-SAT scores run from 5 to 15. A higher score is an indication for more satisfaction with the support provided.

The level of functional ability will be conceived as an indicator of the level of chronic strain. The level of functional ability was measured with the Groningen Activity Restriction Scale (GARS; Kempen and

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Suurmeijer 1990, Kempen et al. 1993, Suurmeijer and Kempen 1990). It has 18 items divided into two subscales: an ADL subscale, assessing Activities of Daily Living (dressing, washing oneself, etc.) and an IADL subscale, assessing Instrumental Activities of Daily Living (mainly household activities). The response categories of the GARS range from: 1) fully independent without any difficulty; 2) fully independent but with some difficulty; 3) fully independent but with great difficulty; 4) cannot do it fully independent, only with someone's help; to 5) cannot do it at all, need complete help. Because the scores in category 4 and 5 did not discriminate, these two categories were merged into one. The GARS runs from 18 to 72. A higher score on the GARS indicates more restrictions. Mokken Scale analysis for Polychotomous items (MSP; Debets et al. 1987, Sijtsma 1990) showed that the items form a strong unidimensional scale of hierarchically ordered items (Kempen and Suurmeijer 1990, Kempen et al. 1993, Suurmeijer and Kempen 1990, Suurmeijer et al. 1994). In another study, the GARS yielded good results with respect to sensitivity to measure change (Doeglas et al. 1995a).

### 7.2.3 *Statistical analysis*

Former analyses of the EURIDISS data has demonstrated that between T1 and T2 patients recovered to some extent from their first symptoms of RA, followed by a more or less constant decrease in functional ability (Doeglas et al. 1995a). To demonstrate the erratic pattern of RA in recent onset cases, changes in functional ability, social support and depressive feelings were described by comparing the mean scores (and their standard deviations) on all four points of measurement. Furthermore, four groups were formed on the basis of the changes in functional ability between two points of measurement: one group that improved in functional ability, one group that deteriorated, and two groups that did not change: one stable group with a high level of functional ability, and one stable group with a low level of functional ability. The change scores were calculated by subtracting the more recent score from the score of the year before. For example:  $\delta_{T1-T2}GARS = GARS_{T2}$  minus  $GARS_{T1}$ . Only differences in functional ability of more than 3 points were considered as a relevant change and, thus, as an improvement or deterioration in functional ability (Doeglas et al. 1995a, Kempen and Suurmeijer 1991). On the basis of their mean GARS score, patients who changed less than 3 points were classified in two groups of stable patients: 50% of the stable patients with a high functional ability (GARS score < 26) and 50% of the stable patients with a low functional ability (GARS score  $\geq$  26). On the basis of these four groups, differences in functional disability will be demonstrated. Furthermore, it was investigated to what extent improvements in functional ability in the one year were followed by a deterioration (or another improvement) in the subsequent year.

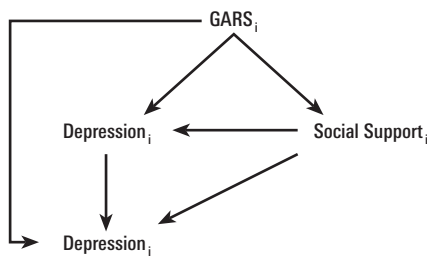


With respect to the level of depressive feelings and the level of satisfaction with the emotional social support (ES-SAT) and social companionship (SC-SAT), it is expected that these scores are depending on the original (early) level of functional ability as well as on the changes in functional ability. To verify this assumption, the scores on depressive feelings and on social support satisfaction were compared for each of the four groups mentioned above. The differences were analyzed with a t test.

Next, in order to investigate the second research question, a hierarchical regression analysis was performed to test the direct and stress-buffering effect of social support. To assess the buffering effect of social support, two interaction terms were computed between functional ability (stressor) and both social support satisfaction scales: ES-SATxGARS and SC-SATxGARS. To reduce multicollinearity between product variables and the separate elements from which the interaction terms were constituted, the sample mean was subtracted from each element and divided by their standard deviation before the cross product terms (stress by support) were calculated (Dunlap and Kemery 1987). A significant relationship between an interaction term and the outcome measure (depressive feelings) -for example in a regression analysis- confirms a stress-buffering effect of social support.

The T1-T4 interval is the maximum period of time covered by our data. We assumed that a long time interval would be most appropriate to demonstrate the buffering effect of social support, since things can more change in a longer period of time. Therefore, it was initially decided to use the data from T1 and T4: depression at T4 as the dependent variable, and the variables at T1 and the changes between T1 and T4 of these variables as the independent variables. Unfortunately, the data from these two waves did not support the buffering effect of social support and it was decided to test the buffering effect on other time intervals. With data from T1, T2, T3 and T4, six different time intervals are possible. For each possible time interval, the buffering effect was tested by means of the same model.

Figure 7.1 The basic model



To determine the sequence of the variables to be entered into the model, a few assumptions were made; see the basic model in figure 7.1, which is based on T1 and T4. First, functional ability at T1 has an effect on depressive feelings at T1 and on social support at T1. Second, social support T1 has an effect on depressive feelings at T1. Third, functional ability and social support at T1 have an effect at depressive feelings at T4. Since depressive feelings at T1 depends on both social support and functional ability at T1, the variance in depressive feelings at T4 must first be explained by functional ability and social support at T1, followed by depressive feelings at T1. First entering depressive feelings at T1 would obscure the effects of functional ability and social support. As a result, the following variables are entered in subsequent steps: in step 1 the background variables sex, age and educational level, in step 2 GARS<sub>T1</sub>, in step 3 ES-SAT<sub>T1</sub> and SC-SAT<sub>T1</sub> at T1, in step 4 the interaction terms ES-SAT<sub>T1</sub>xGARS<sub>T1</sub> and SC-SAT<sub>T1</sub>xGARS<sub>T1</sub>, in step 5 depressive feelings<sub>T1</sub>, and finally in step 6 the change scores  $\delta_{T1-T4}$ GARS,  $\delta_{T1-T4}$ ES-SAT and  $\delta_{T1-T4}$ SC-SAT. Since the sample was selected on early RA (patients with a disease duration of four years or less), disease duration was not used as an explaining variable.

### 7.3 Results

#### 7.3.1 Global results

In table 7.1, the mean scores and standard deviations of the variables involved in this study are presented for all four points of measurement (T1-T4). In general it can be concluded that the mean scores had not changed much between the four points of measurement. For the GARS, the score at T1 is identical to the score at T4; about 32.3. In between these two points of measurement, the patients had improved a little in functional ability. The GARS score at T2 differs significantly from T1 as well as from T4. Although the mean score does not change between T1 and T4, the standard deviation increases from year to year, which indicates that the mutual differences between patients increase. In line with the scores

Table 7.1 Mean scores (standard deviations) for GARS, depressive feelings en social support satisfaction for T1 to T4; n=263

	T1	T2	T3	T4	significance <sup>a</sup>
GARS	32.3 (10.6)	31.3 (10.9)	31.6 (11.4)	32.2 (11.3)	T2 - T1/T4
Depression	8.97 (3.29)	8.70 (2.82)	8.70 (2.61)	8.75 (2.77)	-
ES-SAT	30.6 (3.71)	31.1 (2.89)	31.2 (3.23)	31.3 (3.37)	T1 - T2/T3/T4
SC-SAT	13.7 (1.90)	13.8 (1.89)	13.7 (1.86)	13.8 (1.93)	-

a: p < .05

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on the GARS, also the scores on depressive feelings are comparable at T1 and T4, and lower at T2 and T3. The maximum difference in depressive feelings (.27) is not significant.

With respect to the satisfaction with the social support provided, it can be concluded that the emotional social support (ES-SAT) score increases slowly from year to year. The score at T1 is significant lower compared to the scores at T2, T3 and T4. The social companionship satisfaction (SC-SAT) score does not differ between any of the points of measurement.

### 7.3.2 *Functional ability*

Table 7.2 shows the GARS scores for patients who improved, remained stable (high and low), and deteriorated, respectively, between two consecutive occasions of measurement. Between T1 and T2 the functional ability of 49 patients deteriorated, 84 patients improved, while 130 patients remained stable - of which 61 had a high level of functional ability and 69 patients had a low level of functional ability (see table 7.2). From table 7.2 it appears that the number of patients that improve in functional ability between two points of measurement decreases from 84 (T1-T2) to 57 (T2-T3) till 49 (T3-T4). For the patients that deteriorate in functional ability, the opposite effect is demonstrated. This number increases from 49 (T1-T2) to 68 (T3-T4).

In general, it can be concluded from table 7.2 that the mean GARS score increases slightly in all categories from year to year and, moreover, that patients who improved between T1 and T2, had, on average, higher GARS scores (were more disabled) on T1 (37.2), than deteriorating patients in the same period of time (31.8). This difference is significant, for T1, T2, and for T3 ( $t=3.12$ ,  $p=.002$  on T1; and on T2: 36.9 versus 31.5 -  $t=2.99$ ,  $p=.003$ ; on T3: 40.3 versus 29.9 -  $t=5.28$ ,  $p=.000$ ). Stable patients with a high functional ability had (of course) the lowest GARS score between 20.1 and 20.9. The minimum score of the GARS is 18. The stable groups with a low functional ability had mean scores of about twice as large.

The differences between T1 and T2 were similar to the differences between T2 and T3 and T3-T4. On average the scores of the deteriorating groups declined about 7 to 8 points, while the improving groups increased of 7 to 8 points. This was substantially more than the average change for the total group, which amounts to -1.1, +0.4, and +0.6 for the differences between T1-T2, T2-T3 and T3-T4, respectively.

The conclusion that can be drawn from table 7.2 is, that whether one improves (or deteriorates) or not depends on the mean level of functional ability of a patient. Thus, when differences are considered between deteriorating patients and improving patients, one has to

**Table 7.2 Differences in functional ability and depressive feelings for patients who improve, remain stable (high and low) and deteriorate in functional ability, for T1-T2, T2-T3 and T3-T4**

Functional ability						
T1-T2	n	GARS-T1	GARS-T2	ΔGARS	depression-T2	Δdepression
Improved	84	37.2 (9.2)	29.5 (9.2)	-7.7 (3.8) <sup>a</sup>	8.64 (3.07)	-1.01 (2.85) <sup>b</sup>
Remained stable (low)*	69	36.9 (9.1)	38.2 (8.7)	0.4 (1.8)	9.25 (2.99)	0.24 (2.70)
Remained stable (high)	61	20.7 (3.1)	20.2 (2.5)	-0.5 (1.4) <sup>c</sup>	8.07 (2.10)	0.31 (2.10)
Deteriorated	49	31.8 (9.7)	39.3 (10.3)	7.4 (4.5) <sup>a</sup>	8.63 (2.40)	-0.53 (3.25)
T2-T3		GARS-T2	GARS-T3	ΔGARS	depression-T3	Δdepression
Improved	57	36.9 (9.8)	29.5 (9.1)	-7.4 (3.9) <sup>a</sup>	8.93 (2.82)	-0.14 (2.64)
Remained stable (low)	72	37.8 (8.7)	37.8 (8.9)	0.0 (1.9)	8.96 (2.81)	-0.33 (3.02)
Remained stable (high)	72	20.1 (2.4)	20.2 (2.7)	0.1 (1.5)	7.61 (1.00)	-0.04 (1.35)
Deteriorated	62	31.5 (9.9)	39.7 (10.8)	8.3 (4.3) <sup>a</sup>	9.47 (3.09)	0.60 (3.03)
T3-T4		GARS-T3	GARS-T4	ΔGARS	depression-T4	Δdepression
Improved	49	40.3 (10.8)	32.1 (10.7)	-8.2 (4.7) <sup>a</sup>	9.00 (2.95)	0.00 (3.00)
Remained stable (low)	75	37.7 (9.0)	38.0 (9.3)	0.2 (2.0)	8.77 (2.79)	-0.19 (2.53)
Remained stable (high)	72	20.7 (2.7)	20.9 (2.5)	0.2 (1.7)	7.81 (1.33)	-0.28 (1.31)
Deteriorated	68	29.9 (10.1)	37.7 (10.6)	7.8 (5.1) <sup>a</sup>	9.54 (3.47)	0.72 (2.95) <sup>c</sup>

\*: A high score indicates a low level of functional ability

a:  $p < .001$ ; b:  $p < .01$ ; c:  $p < .05$

consider 'the values at the starting point', i.e. the level of functional ability at T1 (or T2 or T3 respectively).

Table 7.3 shows how the changes in one year (between T1-T2) compare to the changes in the following year (T2-T3), and next how the changes between T2-T3 compare to the changes between T3-T4. Table 7.3 shows that 30% (T1-T2/T2-T3) to 44% (T2-T3/T3-T4) of the patients whose functional ability had initially improved in one year, deteriorated the next year. The opposite can be concluded for patients who had deteriorated; 49 to 34% improved in the following year. The cells marked with an asterisk should logically be empty. However, some patients changed not enough (i.e. less than 3 points) to be placed in the category 'improved' or 'deteriorated', but did switch from the high stable to the low stable group or vice versa. For stable patients with a high functional ability, it is (almost) not possible to improve in functional ability. These patients either remain stable or deteriorate in functional ability the following years.

**Table 7.3 Percentages of improving, deteriorating or stable patients, compared with the changes in the preceding year; T1-T2 vs. T2-T3 and T2-T3 vs. T3-T4**

Functional ability	n	Improved	Remained stable low	Remained stable high	Deteriorated	
<i>T1-T2</i>		<i>T2-T3</i>				
Improved	(84)	13%	26%	31%	30%	100%
Remained stable (low)	(69)	28%	48%	1% *	23%	100%
Remained stable (high)	(61)	5%	5% *	73%	17%	100%
Deteriorated	(49)	49%	29%	2%	20%	100%
	(263)					
<i>T2-T3</i>		<i>T3-T4</i>				
Improved	(57)	12%	19%	25%	44%	100%
Remained stable (low)	(72)	25%	47%	4% *	24%	100%
Remained stable (high)	(72)	4%	1% *	73%	22%	100%
Deteriorated	(62)	34%	42%	8%	16%	100%
	(263)					

\* The patients in these categories change less than 3 points, but do change from high to low (low to high) functional ability.

### 7.3.3 Depressive feelings

Cross-sectional correlations between functional ability (GARS) and depressive feelings (depression subscale of the GHQ-28) in the total sample were: .25 (T1), .21 (T2), .21 (T3) and .25 for T4, respectively (all significant for  $p < .001$ ). From this we can conclude that greater functional ability goes together with less depressive feelings. In table 7.2, the mean depression scores are presented for T2, T3 and T4 for the four change groups, as well as the changes in depressive feelings ( $\delta$ depression) for these groups compared to the preceding year. A t test was used to examine whether the differences between the groups were significant. As expected, the lowest score on depressive feelings was found for the stable groups with high functional ability. Compared to these groups, the stable group with low functional ability obtained significant higher scores on every occasion, i.e. patients with a high level of disability had more depressive feelings. The highest scores on depressive feelings (except for T1-T2), were found for the deteriorating groups, which is in line with the expectations. Contrary to the expectations is the fact that patients who improve in functional ability still obtained relatively high scores on depressive feelings.

Table 7.4 Correlationmatrix of the variables assessing depression at T4

	Dep <sub>T4</sub>	Educ	Sex	Age	GARS <sub>T1</sub>	ES-SAT <sub>T1</sub>	SC-SAT <sub>T1</sub>	ES-SAT <sub>T1</sub> xGARS <sub>T1</sub>	SC-SAT <sub>T1</sub> xGARS <sub>T1</sub>	Dep <sub>T1</sub>	$\delta_{T1-T4}$ GARS	$\delta_{T1-T4}$ ES-SAT	$\delta_{T1-T4}$ SC-SAT
Depression <sub>T4</sub>	1.00												
Education	-.19 <sup>a</sup>	1.00											
Sex	.14 <sup>b</sup>	-.09	1.00										
Age	.07	-.26 <sup>a</sup>	-.15 <sup>b</sup>	1.00									
GARS <sub>T1</sub>	.18 <sup>a</sup>	-.13 <sup>b</sup>	.05	.11 <sup>b</sup>	1.00								
ES-SAT <sub>T1</sub>	-.26 <sup>a</sup>	-.01	-.03	.09	-.06	1.00							
SC-SAT <sub>T1</sub>	-.22 <sup>a</sup>	-.01	-.06	-.03	-.16 <sup>a</sup>	.43 <sup>a</sup>	1.00						
ES-SAT <sub>T1</sub> xGARS <sub>T1</sub>	-.13 <sup>b</sup>	-.01	-.03	-.05	.01	.15 <sup>a</sup>	.26 <sup>a</sup>	1.00					
SC-SAT <sub>T1</sub> xGARS <sub>T1</sub>	-.08	-.01	-.06	.04	-.02	.27 <sup>a</sup>	.32 <sup>a</sup>	.57 <sup>a</sup>	1.00				
Depression <sub>T1</sub>	.57 <sup>a</sup>	-.12 <sup>b</sup>	.16 <sup>a</sup>	-.04	.25 <sup>a</sup>	-.33 <sup>a</sup>	-.42 <sup>a</sup>	-.18 <sup>a</sup>	-.17 <sup>a</sup>	1.00			
$\delta_{T1-T4}$ GARS	.10 <sup>b</sup>	-.06	.08	.06	-.28 <sup>a</sup>	.03	.10	-.03	.03	-.08	1.00		
$\delta_{T1-T4}$ ES-SAT	.00	-.03	-.04	-.08	-.04	-.57 <sup>a</sup>	-.14 <sup>b</sup>	.11 <sup>b</sup>	.00	.10	.04	1.00	
$\delta_{T1-T4}$ SC-SAT	-.08	.05	-.09	.06	-.03	-.16 <sup>a</sup>	-.53 <sup>a</sup>	-.11 <sup>b</sup>	-.13 <sup>b</sup>	.12 <sup>b</sup>	-.09	-.27 <sup>a</sup>	1.00

a: p &lt; .01; b: p &lt; .05

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From the change scores in depressive feelings it can be concluded that the groups with no change in functional ability, did also not change in the level of depressive feelings. Furthermore, an improvement in functional ability coincided only at T1-T2 with an improvement in depressive feelings (-1.01;  $p=.002$ ), whereas only a deterioration in functional ability between T3-T4 corresponded with a deterioration in depressive feelings (0.72;  $p=.048$ ). These findings were supported by the correlations for the total sample between  $\delta$ GARS and  $\delta$ depression for T1-T2, T2-T3 and T3-T4: .08 ( $p=.098$ ), .10 ( $p=.052$ ) and .09 ( $p=.071$ ); although weak and not significant. For a T1-T4 interval, however, this correlation is .20 ( $p=.001$ ).

#### 7.3.4 *Social support satisfaction*

Concerning the relationship between changes in functional ability and social support satisfaction, only the patients that remained stable with a high level of functional ability between T1 and T2 were significantly more satisfied with the emotional support provided at T2. These results are not presented in a table. This increase in support satisfaction is contrary to the expectation, since the level of functional ability did not change between T1 and T2. But in general, these results were in line with the bivariate correlations between  $\delta$ GARS and  $\delta$ ES-SAT or  $\delta$ GARS and  $\delta$ SC-SAT: none were significant. Finally, for any point between T1 and T4, the mean level of social companionship satisfaction was weakly related to (the mean level of) functional ability (-.15 to -.25;  $p < .007$ ), indicating that less functional ability goes together with less satisfaction.

Before the results of the hierarchical regression analysis with depressive feelings at T4 will be shown, first the bivariate correlations between all the variables included in the final model are presented (table 7.4). As was assumed in our basic model (figure 7.1), initial depressive feelings (at T1) were significantly associated with functional ability and, even stronger, with satisfaction with emotional support and social companionship. This indicates that more satisfaction (with supportive interactions) is related to less depressive feelings. Also, the interaction between functional ability and these aspects of social support were significantly related to baseline depressive feelings, indicating that functional ability and social support are not independently related to each other. This finds expression in the fact that the relationship between functional ability and depressive feelings is different, i.e. weaker, interrelated for patients who are highly satisfied with their social support, compared to patients who are not or less satisfied. This can be illustrated by the correlation between functional ability and depressive feelings. For T1, this correlation was .30 for the patients with a low level of satisfaction with the support provided, while it was .20 for the patients who were highly satisfied. Although weaker as might be

expected, most of these relation were present as well with depressive feelings at T4. Depressive feelings at T1 was the most important factor for these feelings at T4; a correlation of .57.

To answer the second research question, a regression analysis was performed in six steps (see table 7.5 and the section on 'statistical analysis'). In table 7.5, the beta's, which can be used for mutual comparison, are presented together with the variance accounted for by each step ( $R^2$  change) as well as the total  $R^2$ .

In general, it can be concluded that, except for one, every step implied a significant improvement for the model. The only variables that were no improvement for the model were the two interaction terms, that were specially computed to prove the stress-buffering model:  $ES-SAT_{T1} \times GARS_{T1}$  and  $SC-SAT_{T1} \times GARS_{T1}$ . The most important

**Table 7.5** Regression analysis of functional ability and social support on depressive feelings at T4

	Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
1 Education	-.15 <sup>a</sup>	-.14 <sup>a</sup>	-.14 <sup>a</sup>	-.14 <sup>a</sup>	-.09	-.08
Sex	.12 <sup>a</sup>	.11	.11	.11	.06	.02
Age	.07	.05	.07	.06	.09	.08
R <sup>2</sup>	.05 <sup>b</sup>					
2 GARS <sub>T1</sub>		.15 <sup>a</sup>	.12 <sup>a</sup>	.13 <sup>a</sup>	.04	.07
R <sup>2</sup> change		.02 <sup>a</sup>				
3 ES-SAT <sub>T1</sub>			-.23 <sup>c</sup>	-.24 <sup>c</sup>	-.14 <sup>a</sup>	-.21 <sup>b</sup>
SC-SAT <sub>T1</sub>			-.08	-.07	.06	-.01
R <sup>2</sup> change			.07 <sup>d</sup>			
4 ES-SAT <sub>T1</sub> × GARS <sub>T1</sub>				-.12	-.07	-.04
SC-SAT <sub>T1</sub> × GARS <sub>T1</sub>				.08	.06	.06
R <sup>2</sup> change				.01		
5 Depression <sub>T1</sub>					.48 <sup>d</sup>	.47 <sup>d</sup>
R <sup>2</sup> change					.17 <sup>d</sup>	
6 $\delta_{T1-T4}$ GARS						.16 <sup>b</sup>
$\delta_{T1-T4}$ ES-SAT						-.11
$\delta_{T1-T4}$ SC-SAT						-.13
R <sup>2</sup> change						.05 <sup>c</sup>
Total R <sup>2</sup>	5%	7%	14%	15%	32%	37%

The represented values are the beta's.

a:  $p \leq .05$ ; b:  $p \leq .01$ ; c:  $p \leq .001$ ; d:  $p \leq .0001$



variables for explaining depressive feelings at T4 were emotional social support satisfaction (ES-SAT;  $R^2$  change in step 3 is 7%) and, as was expected, depressive feelings at T1 ( $R^2$  change in step 5: 17%). Besides on depressive feelings at T1 and emotional social support satisfaction, in the final step (6) depressive feelings at T4 also seemed to depend to some extent on the change in functional ability ( $\delta_{T1-T4}$ GARS). In the final model, 37% of the total variance is accounted for.

In table 7.6, an overview is given of all variables that significantly predicted depressive feelings for any of the six time intervals. First, the regression of T4 depression on the independent variables of T1, T2 and T3 are presented, followed by the regression of T2 on T1 and T3 on T1 and T2.

**Table 7.6** All significant variables of the final model assessing depression, for any time interval

	T1-T4	T2-T4	T3-T4	T1-T2	T1-T3	T2-T3
Education		x	x			
Sex						
Age						
GARS						
ES-SAT	x			x	x	
SC-SAT						
ES-SATx GARS		x				
SC-SATx GARS		x				
Depression	x	x	x	x	x	x
$\delta$ GARS	x	x			x	
$\delta$ ES-SAT		x	x		x	
$\delta$ SC-SAT						
Total $R^2$	37%	42%	35%	35%	31%	32%

x Indicates a significant effect for that specific time interval.

Most essentially, it appears from the final models in this table that the buffer effect of social support plays a minimal role. Only in the T2-T4 model, for both types of social support satisfaction a significant interaction term could be demonstrated. The level of emotional support satisfaction at T1 significantly influenced the level of depressive feelings at any of the later points in time, while changes in emotional support satisfaction ( $\delta$ ES-SAT) became more important during the course of the disease. Next, not disability itself, but changes in disability ( $\delta$ GARS) appeared to maintain a direct

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significant influence on depressive feelings. Finally, table 7.6 shows clearly that if depressive feelings once occur, they are most determining for depressive feelings later on in time.

#### 7.4 Discussion

Our results clearly demonstrated the erratic pattern of early RA. On average, the functional ability of patients with RA in our study did hardly change between T1 and T4. The level of depressive feelings and of satisfaction with social companionship did not change, while the level of satisfaction with the emotional support slightly improved between T1 and T4. Although the mean level of functional ability between T1 and T4 did hardly change, this study has demonstrated that on the individual level extensive changes were encountered, which is an indication of the erratic pattern of early RA. Whether or not one improves or deteriorates in functional ability depended to a large extent on the (original) level of functional ability from which this improvement or deterioration resulted. On basis of this finding we may conclude that if change scores in functional ability are to be related to other measures, for example measuring quality of life, it is imperative to consider the level of functional ability from which the changes originated, as well. Furthermore, patients who deteriorated in functional ability during one year, had in general the best chances to improve the subsequent year and vice versa. This phenomenon is known as regression towards the mean. The erratic pattern of early RA makes it difficult for the individual patients to adjust, since their near future is (and remains) very uncertain and unpredictable. Recently, it has been indicated by a statistical specialist that multilevel analysis is more appropriate to analyzing this type of longitudinal data and the erratic pattern that is enclosed in it (Snijders 1996, Snijders and Bosker 1999).

Depressive feelings were only moderately related to functional ability. In line with the expectations, it was demonstrated that stable patients with either a high or a low level of functional ability indeed were not confronted with changes in depressive feelings. Furthermore, the stable patients with less restrictions in functional ability, were less depressed than stable patients with many restrictions in functional ability. Contrary to the expectations, both patients who deteriorated and patients who improved between two points of measurement, indicated to be burdened with a rather high level of depressive feelings. Especially for the patients who improved in functional ability a simultaneous improvement in depressive feelings was expected, i.e. were expected to be less depressive. The correlations between changes in functional ability and changes in depressive feelings were not significant for T1-T2, T2-T3 and T3-T4, for the total sample. The fairly obvious relationship between

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functional ability and depression is perhaps not that obvious at all. As a result, it must be concluded that depressive feelings are not direct-proportional related to the level of functional ability. An alternative or additive explanation for the decreased level of mental well-being in chronic patients may be the degree of uncertainty about the future course of the disease (RA) and its consequences, rather than a decrease in functional ability (Dildy 1996). According to Wiener (1975) uncertainty prevails about whether: '1) there will be any pain, swelling or stiffness; 2) the area of involvement; 3) the intensity of the disability; 4) whether onset will be gradual or sudden; 5) how long it will last; and 6) how frequently flare-ups will occur'. She distinguished two imperatives for the condition of variable uncertainty. The 'physiological imperative', which must be monitored for pain and disability, and the 'activity imperative', which must be acknowledged if one is going to maintain what is perceived as normal life. Differences in the course of the illness do occur as was demonstrated in present and in other studies on RA (Scott and Huskisson 1992), or in other chronic disorders such as multiple sclerosis (Zwanikken 1997). Some patients more often suffer from more illness activity than others, whose suffering may remain fairly constant for years. More changes in illness activity result in more uncertainty and unpredictability in relation to the future course of the illness (Van Lankveld 1993). In this sense, uncertainty constitutes a restriction on the realization of valued objectives, i.e. the realization, the achieving or the maintaining of a high quality of life.

An important goal of the present study was to demonstrate the main and the buffering effects of social support. Theoretically, the presumed buffering effect is thought to be correct, although, until now, only a few studies were able to demonstrate this buffering effect of social support in cross-sectional settings. In the present longitudinal study, the buffering effect of social support was investigated by computing interaction terms between the level of satisfaction with the social support provided and functional ability. Subsequently, the significance of these interaction terms were tested in a regression analysis. Applying this method, no studies with a longitudinal design have succeeded to demonstrate the buffering effect of social support. Before a regression analysis was performed in order to test the buffering effect of social support (the second research question), the involved variables were bivariately correlated first. Most of these variables appeared to be significantly related to depressive feelings at T4: educational level, sex, functional ability, emotional social support satisfaction, and satisfaction with social companionship. Also one of the interaction terms (emotional support satisfaction by functional ability) was significantly related to depressive feelings as well as preceding depressive feelings. In the

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hierarchical regression analysis, only a few of these variables were left in the final model assessing depressive feelings at T4, of which early depressive feelings was most important.

There are two reasons that make the level of early depressive feelings important in assessing later depressive feelings. Depressive feelings at a certain moment of time are related to both former depressive feelings and future depressive feelings. In addition, according to our basic model (figure 7.1) cross-sectional depressive feelings are influenced by both functional ability at that moment and by direct and indirect levels of social support (satisfaction). Therefore, it is not surprising that the preceding level of depressive feelings could be denoted as the most important variable in assessing later depressive feelings. Furthermore, the significance of other encountered variables diminished, when early depressive feelings were entered in the model. However, this doesn't mean that these variables are not important to depressive feelings at T4 any more, but that these variables have an indirect effect, which finds its way through formerly depressive feelings. In this respect, depressive feelings at T1 plays the role of surrogate of the variables that are not significant any more (Bradley 1989). Besides early depressive feelings, also the following variables had a direct effect on depressive feelings at any time: the level of emotional social support satisfaction, changes in emotional support satisfaction and changes in functional ability. The present study has also demonstrated that change scores depend heavily on the level from which the changes originate. In this respect, it was rather surprising to find that the original level of functional ability did not have a significant direct effect on depressive feelings, although this effect had to be taken into account.

Also, it is not clear why in the present study the level of (and the changes in) emotional support satisfaction is relevant for depressive feelings, while social companionship satisfaction had no effect. A possible explanation is that emotional support is provided by significant others, while social companionship is provided by less near others and thus less important.

The results with respect to the buffering thesis of social support were rather disappointing. Only two significant effects (out of 12 possible effects) were found in six different analyses. It is not clear why this study did not succeed in its efforts, since the data was carefully collected and the analyses were accurately performed. However, on basis of this study the buffering effect of social support must be rejected for this group of patients with RA. This result is in line with the cross-sectional pilot study of the EURIDISS-project, in which the authors also failed to demonstrate a buffering effect of social support (Doeglas et al. 1994). Another possibility is that there was too little variance in the level of social support satisfaction for yielding significant results. In line with Riemsma (1998b), Doeglas et al. (1996)

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demonstrated that 80% of the patients were satisfied with the support provided.

The demonstrated course of functional ability illustrates the erratic pattern of RA. The erratic pattern of early RA was perhaps the reason that the buffering effect of social support could not be demonstrated in this study. Some studies, therefore, used methods in which average scores of several waves of data collection were used (Waltz et al. submitted, Suurmeijer et al. Submitted 1). This method is also known as the 'Area Under the Curve' (AUC) procedure (Lydick et al. 1995). These so called 'composite measures' reduce the variations between measurement time points, and thus can be conceived as more stable, representative and valid measures. In future research, this method could be applied in another attempt to demonstrate the buffering effect of social support.

<sup>5</sup> The questionnaires can be found in Suurmeijer et al. (1995) and Doeglas et al. (1996)