Facing the challenge of rheumatoid arthritis
Strating, Mathilde Marchien Hiltje

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Disability, social support and distress in rheumatoid arthritis: results from a 13-year prospective study.

Mathilde M.H. Strating, Theo P.B.M. Suurmeijer, Wijbrandt H. van Schuur
Abstract

Objective. To examine the strength and stability of the relationships between disease-related factors (joint tenderness, pain, and functional disability), social support and distress over time and to investigate to what extent disease-related factors and social support can predict distress in short-term and long-term RA.

Methods. The study is a Dutch extension of the ‘European Research on Incapacitating Diseases and Social Support’ (EURIDISS) and started with 292 patients. After five waves of data collection 129 patients still participated. Composite measures were computed following the Area Under the Curve approach. Interaction terms were computed between functional disability and social support satisfaction. Correlational and hierarchical regression analyses were performed.

Results. In short-term RA disease-related factors and social support were important in determining distress. Also a buffering effect of social companionship was found. In total 51% of the variance in distress in short-term RA could be explained primarily by mean distress over the previous years. In long-term RA disease-related factors remained important in determining distress, but to a lesser extent. Of the variance in distress in long-term RA 17% could be explained, also primarily by mean distress over the years before.

Conclusion. During the course of the disease patients may learn to adjust to their disease and its consequences and are able to maintain a normal distress level. The effect of the disease on psychological distress decreased during these years. Some support for the buffering hypothesis of social support was found in short-term RA, but not in long-term RA.
Introduction

Most studies agree that rheumatoid arthritis (RA) has a strong effect on the psychological well-being of the patient. Several studies found elevated levels of psychological distress in RA patients compared to healthy subjects (1-4). Only a few studies also reported changes in distress over time. In these studies (5-9) no differences in distress between patients with short-term and those with long-term RA were found. found no mean changes in distress in their 3-year study. In all of these studies, however, large intra-individual variation was found, which may be explained by differences in disease-related factors such as joint tenderness, pain and disability (7;10-12), sociodemographic factors such as gender (8;13) and personal and social resources such as coping (for review, see (14)) and social support (15-17).

Social support is expected to play an important role in explaining differences in distress. On the one hand social support may have a direct beneficial effect: patients who are supported feel more warmth and affection and can better cope with the disease than patients who have less social support. This effect is also referred to as the strain hypothesis (18), i.e. a lack of social support may cause strain. On the other hand social support may have an indirect (moderating or buffering) effect. For patients with less support the negative impact of the disease on distress is stronger than for patients with more support. This is also referred to as the vulnerability hypothesis (18).

Previous research (15-17;19) provided support for the direct effect of social support, but inconsistent evidence for the indirect effect (15;20-24), which may be the result of different operationalisations (25). Structural aspects such as network size may have direct effects, whereas buffering effects are more often found when functional aspects of the social network are measured such as perceived availability of supportive transactions (25). Suurmeijer et al. (26) assumed that not the supportive transactions as such are to be considered most relevant for one’s health, but the satisfaction with these supportive transactions, since the amount of supportive transactions may be too much, just right or too little and does not necessarily reflect the needs of the patient. Doeglas et al. (27) showed that satisfaction with supportive transactions was more important for patients’ well-being than the occurrence of supportive transactions as such. However, they could not provide evidence to demonstrate the buffering hypothesis of support satisfaction (23;24).

Most research about social support is cross-sectional and does not distinguish between short-term and long-term effects of predictors of distress. Some predictors have more impact in
the early stages of RA and do not have long-term effects, whereas others become more important or remain effective in long-term RA. In other words, the relationship between RA and distress during the course of RA is not necessarily stable (7). In the first years after diagnosis an elevated level of distress is expected as a reaction to this stressful event, but in the long run patients learn to adapt to maintain a stable and acceptable level of distress. Cummins (28) refers to this process as well-being homeostasis. He suggests that people have a ‘set point’ for well-being and have the ability to return to their baseline well-being when certain stressors influence their well-being. Since psychological adjustment is an ongoing process, the stressors and resources that determine a patient’s distress have different short-term and long-term effects and change simultaneously, due to the erratic pattern of RA and the repeatedly changing adaptation tasks, which are related to the life course of the patients and their social role transitions (29).

The aim of this study is twofold: 1) to examine the strength and stability of the relationships between joint tenderness, pain, functional disability, social support and distress over time and 2) to investigate to what extent joint tenderness, pain, functional disability and social support can predict distress in short-term (≤ 6 years) and long-term (≥ 13 years) RA. More specifically we expect that 1) the strength of the relationships between joint tenderness, pain, functional disability, social support and distress decreases over time and 2) social support has a direct effect as well as an indirect buffering effect on distress, i.e. buffering the effect of joint tenderness, pain and disability.

Methods

Subjects

In the Netherlands between 1990 and 1995 four waves of data collection were carried out as part of the ‘European Research on Incapacitating Diseases and Social Support’ (EURIDISS) (30). The present study is a Dutch extension and includes a fifth wave of data collection carried out in 2003. At the start of the study a number of inclusion and exclusion criteria were formulated (30). These inclusion criteria were: aged 20 to 70, diagnosis of RA according to the 1987 revised American College of Rheumatology (ARA) criteria (31), interval between inclusion and time of RA diagnosis ≤ 4 years. The exclusion criteria were: existence of another physical disorder prior to the onset of RA, malignant RA with systemic vasculitis, and very disabling RA (stage IV according to Steinbrocker functional classes) (32).
The first wave of data collection (T1) started with 292 patients. At the fourth wave (T4) 268 patients still participated. During these four waves clinical data were collected by a research nurse and psychosocial data by interviewers at the patient’s home. After the last wave the still surviving patients were sent a self-report questionnaire. In this 8-year period 50 patients had died, 16 had moved away and became impossible to locate and 73 refused to participate. Consequently, 129 patients participated in the fifth wave of data collection (T5). Compared to T4 and adjusting for the number of patients who died or moved away (N=66), the response rate is 64%. Of the 129 participants at T5 71% was female. Mean education level was 3.2 (sd = 1.0) indicating 9 to 10 years of formal education. Mean age at baseline of this T5-sample was 51 years (sd = 11.9). Mean disease duration at baseline was 1.9 years (sd = 1.1) and at T5 14.2 years (sd = 1.4). Applying the method of Smedstad et al. (3), at T4 6% and at T5 11% of these patients were at risk for clinical distress.

Hardly any significant differences at T4 were found concerning health-related (e.g. clinical status, pain, disability) or psychosocial variables (e.g. distress, coping, social support) between the patients who participated at T5 and those who dropped out because of refusal or death. We did find differences in the percentage of females participating at T4 and T5 (65% vs. 71%). Since more men died after T4 the sample at T5 consisted of more female patients. Furthermore, patients who participated at T5 had a higher educational level (3.2 vs. 2.8 on a 6-point scale) than patients who refused to participate at T5 or who died after T4. And as could be expected considering the age-related inclusion criterion at T1, the sample at T5 was significantly younger than the patients who deceased (50.9 vs. 56.1 years at baseline).

Measures

Distress. The depression and anxiety/insomnia subscales of the General Health Questionnaire (GHQ-28) (33-36) were combined to one measure. Each subscale contains 7 items and answer categories run from (1) not at all; (2) no more than usual; (3) rather more than usual to (4) much more than usual. Scores run from 14 to 56 and reliability (Cronbach’s alpha) of the combined scale was .87. The higher the score, the more distress. Distress was assessed during all five waves of data collection.

Joint tenderness. The Ritchie Articular Index (RAI) was assessed during the first four waves (37). The patient’s reaction to pressure on each of 24 joints was registered as follows: grade 0 =
no pain, grade 1 = patient complains of pain and winces, grade 3 = patient complains of pain and winces and withdraws. The RAI is obtained by adding the scores on all 24 joints.

*Pain.* The pain subscale of the *Nottingham Health Profile* (NHP) was assessed at the first four waves (38). The patient was asked to indicate which 8 statements were applicable to his/her situation by ticking ‘yes’ (2) or ‘no’ (1). Pain scores run from 8 to 16. The higher the score, the more pain. Reliability of the scale was .80.

*Functional disability.* Functional disability was measured during all five waves with the Groningen Activity Restriction Scale (GARS)\(^1\) (40;41), which has 18 items divided across two subscales: an Activities of Daily Living scale and an Instrumental Activities of Daily Living scale. The answer categories run from: (1) fully independently without any difficulty; (2) fully independently but with some difficulty; (3) fully independently but with great difficulty; (4) cannot do it fully independently, only with someone’s help; (5) cannot do it at all, need complete help. The category 5 was merged with category 4, because these categories did not discriminate and category 5 was chosen by only a few patients. The GARS runs from 18 to 72 and reliability (Cronbach’s alpha) of the scale was .95. A higher score refers to more restrictions and thus more disability.

*Social Support.* We used the Satisfaction with Emotional Support (ESS) scale of 11 items and the Satisfaction with Social Companionship (SCS) scale of 5 items of the Social Support Questionnaire for Satisfaction (SSQS) during all five waves (27;42). The absence of discrepancy between actual and desired number of supportive transactions is referred to as satisfaction with social support. Each item was asked twice: first respondents reported whether certain transactions happened and how often and secondly information on the satisfaction with the transactions was obtained by asking the patients whether the transaction(s) happened (1) much less than I like, (2) less than I like, (3) just as much as I like or (4) more than I like. The last response category is not linearly connected with the other three categories, which is not desirable for statistical reasons. Therefore, we considered people who responded ‘more than I like’ as at least having enough support in comparison with respondents who indicated to receive ‘too little’ support, and thus category 4 was combined with category 3 (27). The ESS-scale runs from 11 to 33 and the SCS-scale runs from 5 to 15, reliability of both scales are respectively .90 and .81. A higher score indicates more satisfaction with social support.

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\(^1\) In this study we chose the GARS above the Health Assessment Questionnaire (39). Both instruments have good psychometric properties. The GARS, however, was found to be more sensitive to change (40).
Demographics. On T1 data were collected on gender, age, education and disease duration. Education was coded according to the International Standard Classification of Education (ISCED) (43) and recoded on a 6-point scale ranging from 1 (primary education) to 6 (university degree). Disease duration was measured at T1 as the number of months since the patient was diagnosed with RA, fulfilling at least four of the revised criteria of the American College of Rheumatology (31).

Analysis
Descriptive statistics and correlations were calculated and hierarchical regression analyses were performed. We used distress at T4 as an indicator of distress in short-term RA (≤ 6 years) and distress at T5 as an indicator of distress in long-term RA (≥ 13 years). Mean linear changes in the study variables over time were studied with analysis of variance with repeated measurements, followed by post-hoc tests in case of significant linear changes.

As a consequence of the periodic flare-ups and remissions, which vary in time, the course of RA is highly erratic. Fluctuations analogous to those for biological markers of the disease process may affect psychosocial variables. For example, a disease flare-up can be expected to elicit negative thoughts, which are effectively repressed during disease remission. In order to reduce the variations between measurement time points and to obtain more representative and valid measures, the “area under the curve” approach (44-46) was used. The area under the curve is a summary measure that is calculated by taking the average of several assessments over a certain period. This statistical method is often used to evaluate responses to treatment. To predict distress at T4, the scores on T1, T2 and T3 of the independent variables (except demographics) were summed and divided by three (AUC1-3). Similarly, to predict distress at T5 the scores on T1, T2, T3 and T4 of the independent variables (except demographics) were summed and divided by four (AUC1-4).

Centered interaction terms were computed between joint tenderness (RAI), pain, functional disability (GARS) and both social support satisfaction scales (ESS and SCS) to assess the buffering effect of social support. A significant negative relationship between an interaction term and distress confirms the buffering effect (i.e. the same degree of disability leads to less increase in distress if a patient has high social support satisfaction compared to low social support satisfaction).
In the hierarchical regression only variables that significantly correlated with distress were entered. We followed two different procedures in determining the sequence of variables to enter in the hierarchical regression analyses. Since we are mainly interested in the theoretical explanation of distress, i.e. the pathway from disease to distress, entering mean distress over the previous years at the first step would obscure the effects of the other independent variables. Therefore, the first procedure consisted of entering distress over the previous years in the last step. In accordance with Doeglas et al. (24), the sequence of the other independent variables was determined by the following assumptions. Since demographic characteristics are expected to influence our independent and dependent variables they are included as control variables (17;47-49) first. Next, disease-related variables are assumed to have an effect on distress and on mean social support satisfaction and are therefore entered before the satisfaction with social support scales. Since social support is expected to buffer the effect of disease-related variables on distress the interaction terms are entered next into the model.

In the second procedure we entered mean distress over the previous years in the first step and the other independent variables in the steps thereafter. By following this procedure the additional contribution in explaining distress of the other independent variables next to mean distress over the previous years can be investigated. The results of the first procedure will be presented in tables while the results of the second procedure will be summarized in the text.

Results
Mean changes over time
In Table 1 descriptives of the study variables are presented for the T4 and T5 variables separately. No significant mean changes in pain were found over the first four waves. No significant mean changes in distress and satisfaction with social companionship were found during all five waves. During the first four waves, the mean RAI score decreased significantly (\(F = 3.8; \text{df}_1 = 3; \text{df}_2 = 105; p = .01\)). During the five waves of data collection, functional disability showed a borderline significant mean change (\(F = 2.1; \text{df}_1 = 4; \text{df}_2 = 120; p = .08\), with a significant deterioration between T4 and T5 (\(t = 2.1; p = .04\)). Satisfaction with Emotional Support (\(F = 47.8; \text{df} = 4; p < .001\)) was found to change significantly, between T4 and T5 a significant decrease (i.e. less satisfaction) was found (\(t = 1.0; \text{df} = 122; p < .001\)).
Table 1. Descriptive statistics of T5 sample (N=129) on dependent and independent variables.

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Note. RAI is Ritchie Articular Index; GARS is Groningen Activities Restriction Scale; ESS is Emotional Support Satisfaction; SCS is Social Companionship Satisfaction.

Correlations. Correlations between distress at T4 and independent variables are shown in Table 2 and correlations between distress at T5 and study variables are shown in Table 3. Correlations between distress and the independent variables were inspected at T4 and T5 to explore the stability of the relationships.

At T4 more distress was significantly related to more joint tenderness (r = .31), more pain (r = .38), more disability (r = .24), lower emotional support satisfaction (r = -.34) and lower social companionship satisfaction (r = -.44). At T5 more distress was not significantly related to disability anymore (r = .15), but still related to more joint tenderness (r = .23), more pain (r = .32), lower emotional support satisfaction and lower social companionship satisfaction, although to a lesser extent (respectively r = -.15 and r = -.27).

Other high correlations were found between joint tenderness, pain and disability. The correlations between these variables at T4 were between .68 and .76 and at T5 between .64 and .75. To avoid multicollinearity in our regression analyses we combined these two impairment and disability measures into one factor called ‘impairment-disability factor’ (ImpDis). The correlation between this new variable ‘AUC t-3 impairment-disability factor’ and distress at T4 was .34, at T5 this correlation was .26.
Table 2. Correlations between distress at T4 and demographic variables and AUC1-3 variables (N=129).

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Note. * p < .05; ** p < .01 and # p < .10 (1-tailed). A higher scores on a certain measure refers to more of the characteristic considered. RAI is Ritchie Articular Index; GARS is Groningen Activities Restriction Scale; ESS is Emotional Support Satisfaction; SCS is Social Companionship Satisfaction; RAI x ESS etc. are interaction terms; AUC1-3 is Area Under the Curve variables over T1 to T3; ^1 0 = male and 1 = female
Table 3. Correlations between distress at T5 and demographic variables and AUC1-4 variables (N=129).

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<td>.05</td>
<td>.16#</td>
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<td>14.</td>
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<td>-.08</td>
<td>.09</td>
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<td>-.02</td>
<td>.51**</td>
<td>.32**</td>
<td>.47**</td>
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<td>GARS x ESS</td>
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<td>-.28**</td>
<td>.11</td>
<td>-.03</td>
<td>.06</td>
<td>-.20*</td>
<td>-.22*</td>
<td>-.02</td>
<td>.07</td>
<td>.13</td>
<td>.22**</td>
<td>.42**</td>
<td>.23**</td>
<td>.70**</td>
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<tr>
<td>16.</td>
<td>GARS x SCS</td>
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<td>-.16#</td>
<td>.12</td>
<td>-.04</td>
<td>-.03</td>
<td>-.21*</td>
<td>-.01</td>
<td>-.02</td>
<td>.11</td>
<td>-.02</td>
<td>.47**</td>
<td>.34**</td>
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<td>.76**</td>
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Note. * p < .05; ** p < .01 and # p < .10 (1-tailed). A higher scores on a certain measure refers to more of the characteristic considered. RAI is Ritchie Articular Index; GARS is Groningen Activities Restriction Scale; ESS is Emotional Support Satisfaction; SCS is Social Companionship Satisfaction; GARS x ESS and GARS x SCS are interaction terms; AUC1-4 is Area Under the Curve variables over T1 to T4. ³ 0 = male and 1 = female
Regression analyses. Results of the hierarchical regression analyses with distress at T4 and T5, respectively, as dependent variables are shown in Table 4 and 5.

Table 4. Hierarchical regression of demographic variables and AUC1-3 variables on distress at T4.

<table>
<thead>
<tr>
<th>Predictors</th>
<th>β step 1</th>
<th>β step 2</th>
<th>β step 3</th>
<th>β step 4</th>
<th>β step 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Education</td>
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<td>-.06</td>
<td>-.06</td>
<td>.00</td>
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<tr>
<td>2. AUC1-3-ImpDis</td>
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<td>.30**</td>
<td>.25**</td>
<td>.21**</td>
<td>.05</td>
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<tr>
<td>3. AUC1-3-ESS</td>
<td></td>
<td></td>
<td>-.17*</td>
<td>-.18*</td>
<td>-.10</td>
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<tr>
<td>AUC1-3-SCS</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. SCS x ImpDis</td>
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<td></td>
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<tr>
<td>5. AUC1-3-Distress</td>
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<td></td>
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</tr>
</tbody>
</table>

R²-change (%)
Total R² (%)
F
df₁, df₂

Note. Final model multiple R is .72 * p < .05; **p < .01; # p <.10. ImpDis is impairment-disability factor; ESS is Emotional Support Satisfaction; SCS is Social Companionship Satisfaction; SCS x ImpDis is an interaction terms; AUC1-3 is Area Under the Curve variables over T1 to T3.

Distress at T4

When mean distress over T1 to T3 was entered at the last step (see Table 4), education was a significant predictor in step 1 (β = -.22), but not in later steps. In step 2 the impairment-disability factor was a significant predictor with (β = .30) and remained significant until mean distress over T1 to T3 entered. Both social support measures were found significant in step 3 (β = -.17 and -.28 respectively) and remained significant until mean distress over T1 to T3 entered. The interaction term satisfaction with social companionship x impairment-disability factor was also shown as a significant predictor in step 4 (β = -.22), providing support for the buffer effect of social companionship. In the final model only distress over T1 to T3 was found as a significant predictor. In total 51% of the variance in distress at T4 could be explained (F = 19.11; df = 6, 109; p = .000).

In the second procedure mean distress over T1 to T3 was entered in step 1 of the regression and found as a significant predictor, explaining 48% of the variance in distress at T4. In the next steps the other variables were entered but, as could be expected from the results
presented in Table 4, none of these variables were found to be a significant predictor of distress at T4. The total explained variance in distress at T4 remained 51%.

Table 5. Hierarchical regression of demographic variables and AUC1-4 variables on distress at T5.

<table>
<thead>
<tr>
<th>Predictors</th>
<th>β step 1</th>
<th>β step 2</th>
<th>β step 3</th>
<th>β step 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Gender¹</td>
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<td>.13</td>
<td>.10</td>
</tr>
<tr>
<td>Education</td>
<td>-.21*</td>
<td>-.15#</td>
<td>-.11</td>
<td>-.10</td>
</tr>
<tr>
<td>2. AUC1-3-ImpDis</td>
<td>.18*</td>
<td>.15#</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>3. AUC1-4-ESS</td>
<td>-.03</td>
<td>.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. AUC1-4-SCS</td>
<td>-.18#</td>
<td>-.11</td>
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<td></td>
</tr>
<tr>
<td>4. AUC1-4-Distress</td>
<td></td>
<td></td>
<td>.22*</td>
<td></td>
</tr>
</tbody>
</table>

R²-change (%)  3  3  3
Total R² (%)    8  11  15  17
F                4.48*  4.09**  3.28**  3.36**
df₁,df₂         1, 100  3, 99   5, 97  6, 96

Note. Final model multiple R is .42 * p < .05; **p < .01; # p < .10. ImpDis is impairment-disability factor; ESS is Emotional Support Satisfaction; SCS is Social Companionship Satisfaction; AUC1-4 is Area Under the Curve variables over T1 to T4. ¹ 0 = male and 1 = female

**Distress at T5**

When mean distress over T1 to T4 was entered at the last steps, education was a significant predictor in step 1 (β = -.21) and in step 2, but not in later steps. In step 2 the impairment-disability factor was a significant predictor with (β = .18). Both social support measures were not found significant in step 3 or step 4. In the final model (step 4) only distress over T1 to T3 was found as a significant predictor. In total 17% of the variance in distress at T5 could be explained (F = 3.36; df = 6, 96; p =.005), which is a large reduction in the amount of variance explained by these variables on T4.

In the second procedure mean distress over T1 to T4 was entered in step 1 of the regression and found as a significant predictor, explaining 13% of the variance in distress at T5. In the next steps education, and the other variables were entered, but none of these variables was found as a significant predictor of distress at T5.
Discussion

Distress level in the previous years was the best predictor of distress of patients with both short-term and long-term RA. Although the course of distress was relatively stable on average, the number of people with high distress increased over the years (24;50). Patients who are distressed in the early stages of the disease are at risk for developing ‘chronic distress’.

The relationship of distress with disease-related factors (joint tenderness, pain and functional disability) decreased over time, as expected and in line with Cummins’ idea of well-being homeostasis (28). Even though the homeostasis of the patients in our sample was defeated by their disease they were able to maintain a relatively normal distress level. Patients with short-term RA may have more difficulty in accepting their illness, but during the course of RA they may learn to come to terms with their disease, and learn to cope more efficiently and effectively.

The impairment-disability factor did not make an additional contribution in determining distress in short-term and long-term RA beyond that of distress over the previous years. However, it was shown to be of importance in determining psychological distress in the first steps of the analyses before distress over the previous years entered. In accordance with previous findings, disease-related factors not only determined psychological distress in short-term RA, but also, although to a lesser extent, in long-term RA.

Higher satisfaction with emotional support and higher satisfaction with social companionship are related to less distress in short-term and long-term RA. The strength of the relationship decreased over time, as expected. Satisfaction with emotional support and satisfaction with social companionship were both found as significant predictors of distress in short-term RA, but these effects were captured by mean distress over the previous years.

Although the disease-related variables and social support measures did not make an additional contribution to explaining distress next to mean distress over the previous years, neither in short-term nor in long-term RA, the interplay between these factors is substantively interesting to mention. We found some evidence for the buffering effect: in short-term RA, patients who were satisfied with the social companionship they received, experienced less distress due to their disease compared to patients who were less satisfied with their social companionship. In long-term RA, however, no buffering effect of social support was found. The impact of the disease on distress may have been more sharply intensified in the first years after diagnosis, since the intrusiveness of RA on patient’s lives is higher. The impact of the disease on patients’ distress
was less in long-term RA and our sample showed on average relatively low levels of distress. Therefore, patients may not need social support to buffer a negative impact of the disease.

The results of the two analysis procedures showed different results, i.e. in the first procedure the importance of disease-related factors and social support in explaining distress was shown in the first steps, until distress over the previous years was entered. In the second procedure these effects were not shown and were directly captured by distress over the previous years. We assumed that the impairment-disability factor and social support over the previous years predicted distress at T4 and T5, but these factors also influenced distress over the previous years. These two procedures showed that distress over the previous years mediated the effects of the other variables, since it remained significant whether it was entered before or after the other variables. The effect of the impairment-disability factor and social support became less when entered after distress over the previous years.

Although we had the unique opportunity to use longitudinal data over 13 years, our study also had some drawbacks. For example, our sample size at T5 was fairly reduced compared to that of the first four waves. The participating patients at T5 were significantly younger at T4 than those who deceased between T4 and T5. Since age may be related to our outcome measure, attrition bias may have occurred. Another point of consideration concerns the assessment of psychological distress. The nature of the items and answer categories of the General Health Questionnaire, may have caused the low values of distress in the fairly stable course of distress over time (50). Patients were asked to compare their current status with their usual state of mind. However, this may be colored, since patients may change their internal standards, values and life goals. Patients do not compare their present level of distress to their distress before the diagnosis of RA, but to their ‘new’ — usually higher — distress level. This may even be more the case at the fifth wave since eight years passed by since T4. A last point of discussion is our impairment-disability factor. Although impairment and disability are conceptually different, they are closely linked to each other: disability is most often the result of joint tenderness and pain. Furthermore, in the measurement of these concepts there is some overlap. The items of the pain scale often refer to pain when doing a certain activity, such as walking the stairs, which is also referred to in the disability scale. In other words, pain is not always measured as a perception of pain in itself, but in combination with doing specific activities.

In conclusion, this study is one of the first longitudinal studies investigating the effects of functional disability and social support in patients with long-term RA (more than 13 years).
During the course of the disease patients may learn to adjust to their disease and its consequences and are able to maintain a normal distress level. The effect of the disease on psychological distress decreased during these years. Support for the buffering hypothesis of social support was found in short-term RA, but not in long-term RA. Long-term adaptation processes in RA patients is still a neglected issue and future research should focus more on the stability of the effects of stressors and resources on well-being.
References


(6) Barlow JH, Cullen LA, Rowe IF. Comparison of knowledge and psychological well-being between patients with a short disease duration (<1 year) and patients with more established rheumatoid arthritis (>= 10 years duration). Patient Education and Counseling 1999; 38(3):195-203.


