**Objective.** In this study we examined the differences in perceptions of the patient’s health status between rheumatoid arthritis (RA) patients and their spouses, and correlates of these differences with patients’ and spouses’ well-being.

**Methods.** A sample of 188 couples with one member receiving treatment for RA were selected from the rheumatology clinics in Twente, The Netherlands. The mean age of both RA patients and spouses was 56 years. Respondents completed questionnaires, including estimations of both patients and spouses on the patient’s functional disabilities and pain, and scales on affect and marital commitment for patients and spouses.

**Results.** Differences in estimations of patients and spouses were considerable. Both over- and underestimations of the patient’s functional disabilities by the spouse were associated with the patient’s poorer mental health status. Overestimations of the patient’s functional disabilities were associated with poorer mental health among spouses.

**Conclusion.** It is essential that any support intended by the spouse is in accordance with the patient’s needs. If the patient’s condition is misperceived by the spouse, this can lead to ineffective and inappropriate support being given.

**Key words.** Rheumatoid arthritis; Spouses; Perceptions; Health status.

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**INTRODUCTION**

Rheumatoid arthritis (RA) is a chronic, disabling disease characterized by chronic inflammation of joints, resulting for most patients in progressive joint destruction with deformities and various degrees of incapacitation (1). Disease activity can vary considerably, even from day to day. The disease may start at any age, and women are 2 to 3 times more likely to be affected than men. The cause is unknown. The unpredictable and painful course of the disease has great impact on patients’ quality of life (2). They are confronted with physical consequences, such as...
pain, stiffness, fatigue, and deformities of the joints, as well as functional limitations, e.g., problems with mobility and activities of daily living, such as dressing, washing, walking, and household activities.

The psychosocial well-being of people with RA is often seriously affected during the course of the disease. Feelings of depression, anxiety, uncertainty about the future, and consequences of the disease are often mentioned as problems by RA patients (3–5). Social support from, for example, family and friends may play an important role in the way patients cope with the disease. It has been shown that more social support is related to improved mood (6–8). This direct effect of social support on mood has also been demonstrated among RA patients (9,10).

Social interactions do not have only positive effects on well-being; negative aspects of social interactions can lead to a decline in well-being. In a study among female RA patients, Manne and Zautra (11) found that critical remarks from their spouses were related to maladaptive coping strategies by the patients, which in turn lead to poorer psychological well-being. Kraaimaat et al (12) also found that a high degree of criticism from spouses and limited social support are accompanied by poorer psychological well-being of both male and female RA patients. Two other studies showed that problematic aspects of support were related to increased feelings of depression among RA patients (13,14). In chronic illness, spouses generally appear to be the most important source of emotional and instrumental support for patients (15).

The degree to which support from spouses is perceived as positive or negative may be related to differences in perceptions between patients and spouses about the patient’s health status. Patients’ and spouses’ ideas about an illness may diverge greatly, which in turn can have important consequences for the well-being of both (16). For example, spouses may judge the consequences of an illness as far more serious than do patients. This expresses itself as problem maximization or exaggeration and overprotective behavior on the part of the spouse (15,17). The opposite may also occur: spouses may feel that the consequences of the illness are not as serious as the patient claims, which is expressed as problem minimization (18,19).

The main questions addressed in this study are: what differences exist in the perceptions of patients and spouses about the patient’s health status, and how are these differences related to patients’ and spouses’ well-being?

PATIENTS AND METHODS

Respondents and procedure. Our study was performed among 218 RA patients selected from the outpatient clinics of 7 rheumatologists from 2 hospitals in Twente, The Netherlands. All outpatients in Twente satisfying at least 4 of the 1987 American College of Rheumatology (formerly the American Rheumatism Association) criteria for RA (20) were asked by their rheumatologists to participate in a study on education for arthritis patients. Only those patients with a partner who was willing to fill out questionnaires and, if necessary, join in the education program were included. This partner did not have to be the patient’s spouse, but could also be a son, daughter, sibling, or very close friend. Patients residing in a nursing home and/or aged less than 20 years or over 70 were excluded. Before the intervention, patients and partners completed a questionnaire, and the patients were seen by a physiotherapist for clinical measures. These baseline measurements were used for this study.

Out of 825 RA patients, 238 returned a form stating that they agreed to participate. A composite questionnaire was mailed to each participating patient. Four respondents were unable to find time for the education program, 5 could not participate because they were subsequently admitted to hospital, and 11 did not want to fill out the questionnaire. A total of 218 respondents returned the questionnaires. In the analyses, only the data from 188 RA patients whose partners were spouses were used.

Measures. Both patients and spouses were asked to give estimations of the patient’s functional disabilities and pain. The questionnaire also contained questions for patients and spouses about mental health and marital commitment.

Functional disabilities. Functional disabilities were measured with a Dutch version of the Modified Health Assessment Questionnaire (M-HAQ) (21,22). The M-HAQ includes 8 items that assess the degree of difficulty in the performance of activities of daily living. The scale ranges from 1 (able to perform all activities) to 4 (unable to do any of the activities). The internal consistency of the M-HAQ measured with Cronbach’s alpha was 0.89. For this scale a mean score was calculated.

To assess spouses’ perceptions of the patients’ functional disabilities, a spousal version of the M-HAQ was used. This version was identical to that given to patients, except that spouses were asked to rate how able patients were to perform certain func-
tions. The internal consistency of the spouse’s version of the M-HAQ was 0.90.

Pain. To measure pain, the pain scale of the Dutch Arthritis Impact Measurement Scales 2 (AIMS2) was used (23,24). The scale consisted of 5 items (e.g., “During the past month, how often did your pain make it difficult for you to sleep?”). The possible answers to the individual questions were assigned scores ranging from 1 (all days) to 5 (no days). To obtain a subscale score, the scores on the individual items were first added together. The result was then converted into a score ranging from 0 to 10, where 0 represents “no pain” and 10 “severe pain.” The internal consistency of the Dutch AIMS2 pain scale was 0.83.

To assess spouses’ perceptions of the patients’ pain, a spousal version of the Dutch AIMS2 pain scale was used. This version was identical to that given to patients, except that spouses were asked to rate how much pain patients experienced. The internal consistency of the spouses’ version of the Dutch AIMS2 pain scale was 0.85.

Mental health. The mental health status of patients and spouses was measured using the affect scale of the Dutch AIMS2. The scale comprised two subscales—level of tension (anxiety) and mood (depression). Both scales consisted of 5 items (e.g., “During the past month, how often have you felt tense or high strung?” and “During the past month, how often have you enjoyed the things you do?”). The possible answers to the individual questions were assigned scores ranging from 1 (always) to 5 (never). To obtain a subscale score, the scores on the individual items were first added together. The result was then converted into a score ranging from 0 to 10, where 0 represents good mental health and 10 poor mental health. The score for the overall affect scale was the average of the scores for the subscales. The internal consistency of both scales was good—for level of tension: alpha = 0.88 for patients and 0.89 for spouses, and for mood: alpha = 0.72 for patients and 0.78 for spouses.

Marital commitment. Marital commitment was measured by a 7-item scale originally developed by Rusbult and Buunk (25). For questions like: “Can you imagine somebody else taking the place of your spouse?” and “How important is it for you to have a steady relationship?” patients and spouses could answer with 5-point answer categories ranging from “absolutely not” or “not important” to “definitely” or “very important.” Scale scores ranged from 1 (not at all committed) to 5 (very committed). The scale had good internal consistency for both groups (Cronbach’s alpha = 0.72 for patients and 0.79 for spouses). A mean score was calculated for this scale.

Statistics. Data analysis was done using the Statistical Package for the Social Sciences (SPSS for Windows 8.0, SPSS, Chicago, IL). Differences in rational variables between patients and spouses were compared using paired Student’s t-test. We have classified all patient–spouse dyads in 3 categories depending on the differences in their estimations of the patient’s functional disabilities and pain: spouses overestimating the score, spouses and patients with equal scores, and spouses underestimating the score (equal scores are defined as an exact numeric match between patient and spouse scores). The differences between the 3 groups of spouses (overestimating, equal, or underestimating) were measured by analysis of covariance (ANCOVA) controlled for patient’s age, disease duration, and sex. If the ANCOVA yielded significant differences (α < 0.05), pairwise comparisons between the group of patients and spouses with equal scores, and both other groups, were made using the least squares means. The differences in estimations of patients and spouses on the patient’s functional disabilities and pain, as presented in Figures 1 and 2, are spouse’s score minus patient’s score, standardized by dividing the difference by the patient’s standard deviation.

Ethics. The study was approved by the Ethics Committee of the Medisch Spectrum Twente Hospital in Enschede, The Netherlands.
RESULTS

Sixty percent of the 188 RA patients were women. Their highest level of education completed was primary school for 20%, junior vocational school for 48%, and 32% educated to senior vocational school level or higher. The mean age of the patients was 56.1 (± 9.4), with a range of 28 to 70 years. Mean disease duration was 11.3 years (± 9.2), with a range of 1 to 45 years. Forty-seven percent of the patients had one or more comorbidities.

Of the spouses, 41% were women. Their highest level of education completed was primary school for 17%, junior vocational school for 53%, and 30% educated to senior vocational school level or higher. The mean age of the spouses was 56.3 years (± 9.5), with a range of 30 to 75 years.

We found significant differences between patients’ and spouses’ estimations of the patient’s functional health status (M-HAQ) and level of pain (Dutch AIMS2) (Table 1). Most spouses (40%) overestimated the patient’s functional disabilities; 32% underestimated them (Table 2). In Figures 1 and 2 the distributions of the standardized differences in estimations of patients and spouses of the patient’s functional disabilities and pain are presented. Sixty-five (34%) patient–spouse dyads differed by at least one standard deviation in their estimation of patient’s functional disabilities, and 12 dyads (6%) differed by at least two standard deviations (Figure 1). The majority of spouses (57%) overestimated the patient’s pain, while 23% of spouses underestimated it (Table 2). Sixty-seven (38%) patient–spouse dyads differed at least one standard deviation in their estimation of patient’s pain, and 14 dyads (8%) differed at least two standard deviations (Figure 2).

The classification of all patient–spouse dyads in 3 categories (spouses overestimating patients’ functional disabilities and pain, spouses and patients with equal scores, and spouses underestimating patients’ functional disabilities and pain) yielded the results presented in Table 2. We then wished to relate these differences in estimations between patients and spouses to mental health status and marital commitment for both patients and spouses. We therefore calculated for each group the mean scores for spouses and patients on affect (anxiety and depression) and marital commitment. The results are presented in Table 3.

The mental health of both patients and spouses was significantly related to differences between patients and spouses in estimations of the patient’s functional disabilities. Patients’ mental health was best when spouses’ perceptions of their functional disabilities equalled their own. Both over- and underestimations of patients’ functional disabilities were significantly related to their poorer mental health status. Spouse’s mental health was significantly poorer when spouses overestimated the functional disabilities of the patient. Underestimations by the spouse were not related to poorer mental health in spouses. Differences between spouses and

![Figure 2. Standardized differences in estimations of patients and spouses of patient’s pain.](image)

Table 1. Differences in patients’ and spouses’ estimations of the patients’ functional disabilities and pain*

<table>
<thead>
<tr>
<th></th>
<th>Patient, mean (SD)</th>
<th>Spouse, mean (SD)</th>
<th>t</th>
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</thead>
<tbody>
<tr>
<td>Functional disabilities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(M-HAQ)</td>
<td>188</td>
<td>1.56 (0.56)</td>
<td>1.63 (0.59)</td>
</tr>
<tr>
<td>Pain (Dutch AIMS2)</td>
<td>177</td>
<td>5.32 (2.08)</td>
<td>6.02 (2.09)</td>
</tr>
</tbody>
</table>

* M-HAQ = Modified Health Assessment Questionnaire; AIMS2 = Arthritis Impact Measurement Scales 2.
† P < 0.05.
‡ P < 0.001.

Table 2. Number of spouses overestimating, having equal scores, and underestimating the patients’ functional disabilities and pain

<table>
<thead>
<tr>
<th></th>
<th>Functional disability</th>
<th>Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Spouses overestimating</td>
<td>76</td>
<td>40</td>
</tr>
<tr>
<td>Equal scores</td>
<td>52</td>
<td>28</td>
</tr>
<tr>
<td>Spouses underestimating</td>
<td>60</td>
<td>32</td>
</tr>
</tbody>
</table>
patients in estimations of the patient’s pain were not significantly related to the affect and marital commitment scores of patients and spouses.

**DISCUSSION**

In this study we investigated the differences regarding the perceptions of patients and spouses about the patient’s health status, and the relationship of these differences with the well-being of both patients and spouses. We found considerable differences in the estimations of patients and spouses about the patient’s functional disabilities and pain. The actual percentages of disagreement, 72% for functional disabilities and 80% for pain, are to be expected, as we classified only exact equal scores between patients and spouses as agreement. However the degree of disagreement was considerable, with 34% showing a difference of one standard deviation or more for functional disability and 39% showing a difference of one standard deviation or more for pain. Patients’ and spouses’ differences in estimations of pain were larger than those of functional disabilities. Spouses probably have a better understanding of the patients’ functional disabilities than of experiences of pain because functional disabilities are visible while pain is not. In general, spouses perceived the patient to be having more functional disabilities and more pain. This is in accordance with previous research among cancer patients and their spouses (26,27).

Although the differences between patients’ and spouses’ estimations of functional disabilities were less significant than the differences in estimations of pain, the former were more strongly related to patients’ and spouses’ mental health scores. Patients and spouses scoring equally on the patient’s functional disabilities tended to have better mental health scores. Both underestimation and overestimation of the patient’s functional disabilities by the spouse are related to poorer mental health in patients. Spouses who overestimated the patient’s functional disabilities had poorer mental health than spouses who underestimated the patient’s functional disabilities or who agreed with the patient about the patient’s functional disabilities.

Miaskowski et al (28) found that differences in the perception of the pain experience between cancer patients and their family caregivers were associated with deleterious outcomes for the patient on mood and quality of life and for their family caregivers on caregiver strain. They only studied differences in the perception of pain, and not differences in the perception of functional disabilities. Heijmans (16) found that minimization of the seriousness of the disease on the part of spouses of patients with Addison’s disease appeared more detrimental for the patient’s adjustment than maximizing it. Croyle and Hunt (29) found that minimization of the seriousness of an ambiguous health threat, even by a relative stranger, resulted in lower levels of perceived threat on the part of the patient. We found that underestimations of functional disabilities, as well as overestimations, by the spouse were related to poorer affect scores in patients.

In general, maximization by the spouse has been found to negatively affect patient’s well-being. It supports sick role behavior on the part of the patient and leads to negative consequences for the patient, such as increased dependency, lowered competence, and greater depression (15,30–32). This is in accor-
dance with our finding that overestimations of the patient’s functional disabilities by the spouse were associated with significantly poorer mental health in both patients and spouses. Overestimations by the spouse can result in overprotection, which is associated with a variety of negative outcomes (31,33–35). One reason why overprotective care produces these negative effects is that it may make it difficult for the recipients to maintain feelings of control over their own lives. Increases in emotional support are associated with a more internal locus of control up to a point. Beyond that, more emotional support is related to less internality in control (15).

Minimizing the seriousness of being chronically ill may give the patient the impression of not being taken seriously. In the literature on social support and chronic illness, for example, problem minimization is commonly seen by the patient as unhelpful (19). Therefore, expression of minimization by the spouse may also have negative consequences for the well-being of the patient. Underestimations of the seriousness of the disease by the spouse can result in criticism, which may also produce negative effects (15). Manne and Zautra (11) found that women with arthritis whose husbands were highly critical had poorer adjustment and engaged in less adaptive coping behaviors than those whose husbands were uncritical. Kraaimaat et al (12) found that criticism by the spouse significantly contributed to anxiety in male patients and to depression and anxiety in female patients.

The design of our study was cross-sectional; therefore we cannot draw conclusions as to cause and effect. To test causal hypotheses, a longitudinal study with two or more measurements at different points in time is necessary. We think it is likely that differences in estimations between patients and their spouses may cause misunderstandings and therefore influence affect scores and marital commitment of patients and spouses. This is also the leading focus in the literature (15,16,28). However, it is also possible that when patients are more depressed, or when spouses themselves are more depressed, spouses tend to see the patient’s functional status as worse. Other explanations might also account for the differences found, e.g., spouses who are more distressed might not be paying as much attention to the sick partner and thus not give as accurate an estimation. Patient factors might also play a role. In many cases the patient does not perform daily living activities in front of the spouse, or performs them but does not show the spouse how difficult it is or does not want to complain to the spouse about the difficulty. Thus, the patient’s lack of expressivity might cause the discrepancy.

Given our results, and the available theory on the reactions of spouses to chronic disease in their partners, it is essential that any support intended by the spouse is in accordance with the patient’s needs. Misperception of the patient’s condition by the spouse can lead to ineffective and inappropriate support being given. This is the case when the patient’s functional disabilities are over- or underestimated, which can be detrimental to patients’ and spouses’ well-being. Leventhal et al (36) argued that diverging views on an illness between family members can constitute a great source of stress.

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Patients’ and Spouses’ Health Perceptions in RA


